An invisible workforce: understanding the issues and needs of family carers in India

Baseline Study Report
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Carers Worldwide is an organisation working for the development and welfare of the caregivers, which need to be acknowledged and appreciated. Caregivers need to be recognized and identified, as they are the workforce relieving government responsibility of providing care for the disabled, chronically ill and elderly individuals. Carers Worldwide has recognised the efforts of the caregivers and is working towards their wellbeing, an initiative that is worth recognizing and their efforts need to be supported.

The presence of a person with chronic illness/condition impacts family functioning. The caregivers face the brunt and their needs are often forgotten and unrecognized. Research studies have reported this as burden of care. Often professionals design programmes for the affected individuals, the caregivers are expected to continue to care, without looking at their wellbeing. The National Health programmes aim at providing care using community based approaches, which is based on the premise that the locus of care would remain with the caregivers. Families receive very limited support and guidance from professionals and are often looked at as plentiful resources in the community, who are compensating the poorly funded health system in India. If the caregivers are providing sustainable care, it is both ethical and imperative that their needs have to be understood and addressed in a strategic and systematic manner.

By supporting individual caregivers, we are supporting whole families and communities. When a caregiver falls sick, or becomes so worn down by the needs around them, then the whole family and community suffers. It is important to note that in many cases, without these caregivers, caring does not happen.

While working with the caregivers, Carers Worldwide has paid meticulous attention to collection and maintenance of individual records at the partner organizations, SACRED in Andhra Pradesh, SAMUHA in Karnataka and NBJK in Jharkhand. This has made it possible for Carers Worldwide to undertake a focused research to understand the baseline or the point of departure of the caregivers with whom it works.
The strengths of this research initiative are many: most importantly, it has been
designed within an ongoing, multi location, multi culture, multi regional context and
the involvement of the implementers and the affected community has to be recognized.
In doing so, the research questions, design, methodology and execution have
incorporated the experiences of front line field workers who have a robust
understanding of their community.

Carers Worldwide has included research as one of the important components of their
model. This definitely arose from the belief of involving affected people in the research
process, thereby empowering them with information about themselves, so that they
would advocate for their rights. This is the first time an effort has been made at this
grassroots level to build evidence about the day to day lives of caregivers and the
impact of caregiving on their lives. Carers Worldwide has taken the initiative to involve
the partner organizations in collecting data. They have seen the importance of
research in parallel to providing the services in order for caregivers to be recognized.
All other organizations need to learn from their research experience and reflect for up-
scaling the same in their programmes. The findings of this report should not remain in
paper or with the funding organization, they need to be taken back to the people for
whom the research was carried out. The findings will also serve the purpose of
sensitizing the community and larger society.

Probably for the first time in India, an organization has identified the core issues
affecting the caregiver and taken the need for their wellbeing as a motto of the
organization. Caregivers as valuable resources whose experiences can be meaningful
to create community awareness and help fight stigma has also emerged as an
important finding. The research has highlighted the fact that caregivers need to be
supported and nurtured through programmes for their wellbeing. It is hoped that the
authors would continue to take forward their research activities in understanding
caregiving as a multilayered, multidimensional process that changes overtime,
requiring role adaptations and skill acquisition by the families. Carers Worldwide
needs to take this research initiative forward by identifying critical components for
interventions in both rural and urban areas, validating through further research and
then developing a manual to equip grassroots level organisations to support and
empower family caregivers.

I wish the team every success

Dr. N. Janardhana

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I would like to express our sincere gratitude to those who contributed their time, experiences, knowledge, and information to the study. Without their support and contributions, this study would not have come to fruition.

Special thanks go to the carers of relatives with disability or mental illness in Kurnool district of Andhra Pradesh State, Koppal district of Karnataka State and Hazaribagh district of Jharkhand State for allowing us to capture their life experiences. Also, I am sincerely thankful to all the staff of SACRED, SAMUHA and NBJK in these districts who visited the field to collect data for this report. Their efforts have enabled us to learn about carers’ issues and needs in relation to their health, wellbeing and economic situation.

Without support from Dr Mary Wickenden at University College London, Dr N Janardhana and Ms Joice Steffi from the National Institute of Mental Health and Neurosciences (NIMHANS), Catherine Garsed and Ruth Patil from Carers Worldwide, this study and the report would not have been possible. I truly appreciate their suggestions and excellent advice, which have brought this report into its final form; particularly in the areas of developing the tool, their technical contributions to the research, numerical data inputting, analysis and interpretation of the data and preparing of the report.

Further, I would like to acknowledge the support we received from the BasicNeeds Policy and Practice Directorate in India, particularly to Shoba Raja for sharing her experiences of conducting baseline surveys and to Dr Alan Quirk at King’s College London for allowing us to adapt the Carer Wellbeing and Support questionnaire for use within our baseline tool.

Finally, I am very grateful to the Commonwealth Foundation for their financial support of our work with SACRED, SAMUHA and NBJK. Their support has enabled this study to be completed, as an integral part of ‘Promoting the Recognition and Inclusion of Carers of the Disabled and Mentally Ill in India’.

Dr Anil K Patil
Founder and Executive Director
Carers Worldwide
August 2016
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# Abbreviations

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<td>CA</td>
<td>Carers Association</td>
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<td>CSO</td>
<td>Civil Society Organisation</td>
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<td>DP</td>
<td>Disability Pension</td>
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<td>INR</td>
<td>Indian Rupee</td>
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<td>LMICs</td>
<td>Low and Middle Income Countries</td>
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<td>NBJK</td>
<td>Nav Bharat Jagruti Kendra</td>
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<td>NGO</td>
<td>Non-Governmental Organisation</td>
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<td>NIMHANS</td>
<td>National Institute of Mental Health and Neurosciences</td>
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<td>HIV/AIDS</td>
<td>Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrome</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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<td>SACRED</td>
<td>Social Action for Child Rehabilitation, Emancipation and Development</td>
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Executive summary

Unpaid family carers represent the most dominant source of care provision worldwide, providing for the daily needs of millions of disabled and chronically ill people. While the majority of carers provide care gladly, the experience of caregiving creates a heavy burden for many, impacting negatively on carers’ health – both physical and mental – and their financial situation. Extensive caregiving can also lead to carers becoming isolated and socially excluded. In developing countries, unpaid family carers are believed to face a particularly acute burden of care as they all too often must provide care without the support of any social welfare systems, in the face of significant poverty and often within strictly-delineated gender roles. However, there is very little data about the situation of carers in low-income settings and few narratives of care from low-resource contexts. What is apparent, is that support for carers in these contexts is virtually non-existent, not only because of a lack of state welfare systems, but also because few NGOs consider the needs of carers. Where NGOs do work with carers, they overwhelmingly focus on the carer’s role in ensuring the wellbeing of the person they care for, rather than the wellbeing of the carer themselves. Recognising this need, Carers Worldwide was established in 2012 as the only charity to exclusively work with carers in developing countries.

Aware of the huge evidence gap concerning carers in low and middle income countries, Carers Worldwide conducted this baseline survey in 2015, both to build an evidence base of the situation and needs of unpaid family carers in a low-income context and to form a baseline against which programme outcomes could be measured to test the efficacy of the Carers Worldwide model. Furthermore the outcomes of this study have been used to inform the design of further carer support programmes as well as to support and strengthen advocacy messages to influence decision-makers and policy-makers to address the needs of carers.

1540 caregivers participated in the study, all of whom are providing care for a family member with severe disability or mental illness. Carers Worldwide developed a baseline data collection survey, including a measure of wellbeing scale, adapted from the Carer Wellbeing and Support questionnaire developed by Quirk et. al (2012) for assessing wellbeing in carers of people with mental ill health or dementia. This survey was administered to all carers on a one to one basis. Data was also collected about the family members receiving care.

All but a handful of carers surveyed were adults, with the vast majority (82%) aged between 21 and 50. The data further revealed that 84% of carers were female and that the mothers were the most common caregivers, providing 46% of care. 94% of carers were married and the majority (64%) lived in nuclear families. Most carers (59%) had no formal education at all and 61% had no form of employment, citing the lack of available work and being unable to find anyone else to take care of their disabled family member as reasons for not working. Those carers who were employed were primarily engaged in handicraft activities or agriculture, with the majority (90%) earning no more than 3000 INR per month, though many carers also reported having additional sources of income within the household, primarily from the disability pension of the person they care for. A small but significant percentage of carers (14%) had also taken out loans.

27% of carers reported having a specific health problem, some of which may be attributable to their caring activities. However, when carers were asked about their wellbeing more generally, the number of carers reporting concerns about their physical and mental health increased and
significantly. 56% of carers reported ‘a lot’ or ‘quite a bit’ of concern about their physical health and 61% and 60% of carers reported significant (‘a lot’ or ‘quite a bit’) concern about feeling anxious and depressed respectively. Just under half of carers (46%) were members of some kind of self-help group and 11% were involved in other community groups.

The disabled and mentally ill family members receiving care from these caregivers were mostly aged under 40 (80%) and there were more male care recipients (61%) than female care recipients (39%). Care recipients were living with a wide range of impairments, including physical and sensory impairments, learning disabilities and mental illness. Only 8% of care recipients were employed and, like their carers, they were mainly engaged in handicrafts and agricultural labour. 41% of care recipients were members of some form of self-help group within their community.

Using an adapted version of Quirk et. al’s Carer Wellbeing and Support questionnaire, carers were asked to rate their concerns about various aspects of their caring role. Carers reported significant levels of concern in all areas, but indicated particularly acute levels of concern about not having enough time for themselves and not being able to take a break from caring as well as anxieties about the strain their caregiving duties were putting on their relationships with friends and family, with many expressing concern that they were drifting apart from friends. A large number of carers reported significant concern about the impact of caring on their physical health, as well as on their financial situation and many reported feelings of depression and anxiety. Almost without exception carers indicated that they would like more support in their caregiving role.

While this study sought to gain a comprehensive picture of the situation of caregivers in low-income settings by collating data from a large study population and using a tried and tested tool to measure carer wellbeing in addition to comprehensive sociodemographic data, there are nevertheless some limitations to the study. Firstly although care was taken to standardise data collection forms across all 3 study sites, data was collated by a number of people and was not always recorded in a consistent way, making it sometimes difficult to extrapolate the relevant data. Furthermore, although the data collection tools were designed and/or adapted specifically for the context of this study, due to limited resources they were not validated with an Indian population before use and therefore could have been better optimised to capture data more accurately. Finally, if qualitative data had also been collected, it would have been easier to understand and explain some of the interesting trends arising from the data. Due to the contextually-specific experiences of the carers involved in this study (as can be seen by a number of significant variations in data between the different project areas) the outcomes of this study cannot be generalised outside of the Indian context, or indeed, across India.

Despite these limitations, the data has richness, provides results that significantly complement the existing literature on the topic and provides new frameworks and perspectives for research and practice. However, despite the value that this research adds, we must not be complacent – there is still so much more to do – more research is needed to fill this vast research gap, not just to inform programmatic innovations, but also to support much-needed advocacy work to secure basic rights and state support for carers in low-income settings and to raise awareness of the issues this vulnerable, largely invisible population faces.
Background to the study

Study rationale

This baseline study was designed to assess the current situation of carers in India, to inform the design of programmes and the development of project logframes for interventions to support carers. This study also serves as a baseline against which to evaluate the impact of such programmes. Specifically this dataset will be used to evaluate the impact of a carer support intervention funded by the Commonwealth Foundation and delivered by Carers Worldwide through our partner organisations NBJK, SAMUHA and SACRED. This study marks the first time Carers Worldwide has systematically collated and analysed data to assess the situation of unpaid family carers in India. This study serves as an important reference point for programme evaluation and, when combined with a final evaluation report, forms part of a robust monitoring and evaluation process, which represents an excellent opportunity to demonstrate the efficacy of the Carers Worldwide model. Furthermore, the evidence generated from this study will be used to support advocacy work to influence policy- and decision-makers of the need to support carers, as well as being used to illustrate to potential donors the importance of working with carers.

Study objectives

The overall objectives of this study are to:
1. assess the situation and needs of the carers and care recipients in the project areas.
2. establish a baseline for the Commonwealth Foundation-funded carers support project against which to measure outcomes as per the project logframe
3. provide quantitative and qualitative evidence about the situation of carers in India to share with policy- and decision-makers and other NGOs to motivate and inform improvements to services and policies relating to carers
Project description

The Commonwealth Foundation funded project is a partnership between Carers Worldwide and NBJK, SACRED and SAMUHA, which will develop and deliver carer-specific services designed to reduce carer burden and improve the quality of life of carers and those for whom they care. Carers will be encouraged to participate in their own development by developing carer groups into carer associations, empowering them to demand their rights and services from the government at local, state and national levels.

The project will target a group of 1,200 carers (estimated 76% female) of people living with severe disability or mental illness, as well as the people they care for (n = 1,200) and their approximately 3,600 family members (who will benefit from raised family income levels). The beneficiaries are spread across the three project areas served by the three partner organisations. Some have been involved in previous pilot projects, while others are being included in a carers’ project for the first time.

The project is based around 7 themes:

1. **Capacity building**: of partner organisation staff, community mobilisers and carers, through training, support in the field, engagement with the government and other key players in existing civil society structures

2. **Building evidence of need**: through identification and assessment of 1,200 particularly vulnerable carers

3. **Awareness raising**: with carers, families and communities to ensure full recognition of the contribution carers make and the need to address their exclusion

4. **Participatory governance**: establishing a network of carers' groups to build a structure for coordinated participation and engagement with government and other stakeholders; promotion of 3 district level carers’ associations (CAs) to act as an umbrella body for local carers; training nominated carer representatives in organisational development, gender issues, self advocacy, participatory governance and carers’ social, economic and inclusion rights; supporting CAs to function as independent CSOs who will engage with civil society to promote a carers’ movement and work directly with government and other stakeholders to achieve recognition, rights and services

5. **Active engagement**: with local, state and national government officers in the Departments of Health, Rural Livelihoods, Women and Children and Social Welfare and within local, state, and national NGOs to raise the issue of carers and their needs and to highlight ways in which carers can be included in existing schemes and programmes

6. **Health provision**: appropriate to meet carers' health and emotional needs

7. **Poverty reduction**: identifying income generating activities (IGAs) for carers most impacted by poverty and facilitating their involvement in IGAs through provision of high quality alternative caring arrangements
Carers Worldwide highlights and tackles the issues facing carers. We are the only organisation working exclusively with carers in developing countries.

Carers Worldwide is a UK registered charity (1150214) and a UK company limited by guarantee (8083816). Its objective is to promote the relief of people who require care due to physical or mental ill health, disability, old age, frailty, substance misuse or any other cause, in particular (but without limitation) by:

- raising the awareness of carers and the general public to the needs of and difficulties experienced by individuals as a result of their caring role;
- relieving financial hardship, illness and distress among carers; and
- providing relief to cared-for individuals by improving the quality of their care and rehabilitation through the provision of training, support and advice to carers

In pursuance of this objective, Carers Worldwide’s purpose is to bring about ‘sustained positive change for carers in developing countries by addressing issues of recognition, social and economic concerns’.

Carers Worldwide is the first organisation to have identified the need to specifically support and target carers in developing countries. Our work, through the Carers Worldwide model, crosses sectors (mental health, disability, the elderly, HIV/AIDS, education, livelihoods) and has the potential to influence the practice and policy of NGOs and governments.

The strategic goal of Carers Worldwide is to serve as a catalyst to:

- bring about systemic change in the work of governments, charities and other agencies so that they recognise and respond to the needs of carers in the developing world
- facilitate the provision of support for individual carers and their families in the developing world, bringing them better health, wellbeing and economic security

Carers Worldwide achieves its strategic goals by:

- working in partnership with established charities and other organisations that are skilled in service delivery for those in need and are well networked in their communities, in order to create systemic changes in attitudes and support for carers
- disseminating the Carers Worldwide holistic model of the support provision necessary for effecting systemic change for carers
Carers Worldwide has worked in partnership with three NGOs in India since 2012 – NBJK, SAMUHA and SACRED - conducting a 12 month pilot project 'Catalysing Action for Carers', aimed at testing and refining the Carers Worldwide model. This new project will upscale our work with these three organisations, all of who have recognised the significant contributions of unpaid family carers.

Nav Bharat Jagruti Kendra (NBJK)
NBJK is a development organisation working in the Indian states of Bihar and Jharkhand. The organisation was established in 1976. Their mission is to educate, organise and empower the rural poor by promoting development as a liberating force for achieving social justice, economic growth and self-reliance. NBJK’s local partner organisations support rural people impacted by poverty through vocational training, loan programmes, self help groups and employment placement services in 22 districts in Jharkhand and 38 districts in Bihar.

SAMUHA
Based in Northern Karnataka, Samuha has undertaken community development programmes since 1987 with a special focus on vulnerable people, including people living with HIV/AIDS and disabled people. 'Samarthya', the disability unit of SAMUHA, has been working through self-help groups and community-based organisations of disabled people at the taluk, district and state levels. Samarthya also acts as a resource group for other programmes on disability issues through training, exposure visits and guidance. Samarthya works with more than 3,700 people with disability or mental illness in 3 districts – Raichur, Koppal and Karwar.

Social Action for Child Rehabilitation, Emancipation and Development (SACRED)
SACRED is a non-profit, social, secular voluntary organisation, which is committed to the most deprived and under-privileged sections of society. The main aim of SACRED is to equalise disabled people alongside non-disabled people and to encourage them to actively participate in their own development. SACRED started work in 1997 with 2 villages and later expanded to 40 villages in Anathapur district and 56 villages in Kurnool district. They are currently working with over 1,200 people with disability or mental illness.
Review of the literature

Around the world, the daily needs of millions of disabled and chronically ill people are met by informal carers. This invisible force of family members, relatives, friends and neighbours provide practical support, day-in, day-out, to people who, as a result of disability, chronic illness or age, face difficulties in completing activities of daily living (Savage and Bailey 2004). Despite receiving no payment, minimal support and little respite, unpaid carers represent the most prevalent source of care provision worldwide, even where formal care services exist (WHO, 2003). Families are a critical source of support for disabled people and regularly absorb the additional demands on time, emotional resources and financial resources (Baker-Ericzen, Brookman-Frazee and Stahmer, 2005) that are associated with caring for a disabled relative. In India - where this baseline study was conducted – as in most of the non-western world, families have long been the mainstay of caregiving for disabled people, taking care of their daily needs, monitoring their mental wellbeing, identifying early signs of illness, relapse and deterioration and helping them access services. Family caregivers may also supervise treatments and provide emotional support to the person they care for.

Although often undertaken voluntarily, caregiving creates a heavy burden for caregivers (Whitlatch and Noelker, 1996) and a substantial body of data documents the adverse impacts caregiving has on carers (e.g. Brown and Mulley, 1997; Henwood, 1998; Keeley and Clarke, 2002). The strain borne by carers is often referred to as ‘caregiver burden’ (Stucki and Mulvey, 2000). First defined by Treudley (1946) as the negative impact of caregiving on caregivers’ mental health and quality-of-life, caregiver burden is a multidimensional response to the physical, psychological, emotional, social and financial stressors associated with the caregiving experience. Hoenig and Hamilton (1966) explain that this burden can be either objective or subjective. The objective burden refers to the tangible and observable effects of caregiving on the family (e.g. disrupted family routines, constraints on family's social and leisure activities, financial costs), whereas the subjective burden refers to the caregiver's negative appraisal of their circumstances and includes feelings of loss, guilt, shame and anger.

Caregiver burden is a universal phenomenon and has been reported around the world, from Europe and America to Africa, Asia and the Middle East. In developing countries, unpaid family carers face a particularly acute burden of care as the social security systems which might offer support to the families of disabled people are not well developed. Furthermore, their situation is frequently exacerbated by poverty and gender. This chronic lack of support exacerbates both the challenges of living with functional impairment and the challenges of caring for someone with a functional impairment. Therefore, disability can adversely affect not only the disabled person, but their family too and particularly the carer who must meet their specific needs. Faced with ill health, social stigma, exclusion and reduced earning ability, carers in developing countries are a highly vulnerable group.

In this context, it has been observed that if a heavy care burden causes a carer’s wellbeing to deteriorate, so too the quality of care they provide deteriorates, impacting negatively on the wellbeing of the care recipient (Arksey et. al, 2003/2004). However, while many charities exist to support people with disabilities or chronic illnesses, few recognise the vital role that carers play. Evidence from developed countries shows that the vast majority of formal care interventions only
address the needs of care recipients and fail to consider the needs of carers (WHO, 2013).

Where interventions include carers, they focus on the carers’ role in safeguarding the wellbeing of care recipients, rather than carers’ own wellbeing (Arksey et al. 2003/2004). A 2012 review of Indian NGOs found that despite claims by many organisations of supporting carers, in fact these organisations focused overwhelmingly on only supporting carers to improve outcomes for care recipients (Patil).

One body of literature that has seen increasing awareness of the role of caregivers in recent years, is the long-term management of people living with psychiatric illnesses. There is a growing body of literature exploring and documenting caregiver burden, poor caregiver outcomes and the lack of support for caregivers of people with psychiatric illnesses. In turn there have been an increasing number of interventions aimed at alleviating caregiver burden, as well as recognition that the emphasis in psychiatric rehabilitation needs to shift from a patient-focused approach to a combined patient and caregiver focused approach. However, academic literature has largely failed to fully understand caregivers’ psychological distress or the complex and multilayered phenomenon of care-giving in any great depth. Very few studies have investigated the interaction between the characteristics of the cared for person and the attributes of the carer, or the support mechanisms, which ultimately determine the burden of care experienced by caregivers.

Governments, NGOs and other agencies in low and middle income countries (LMICs) have consistently neglected carers and failed to engage with them. In high income countries, there is a thriving network of agencies working with carers, as well as government provision to ensure social protection for carers. In LMICs, there is no government recognition of the role carers play and no organisations addressing the needs of carers. Furthermore, due to their caring responsibilities, carers often cannot access mainstream development activities or local government programmes. As a result of this lack of recognition and support and the associated invisibility and exclusion they experience, carers are denied their basic human rights.

Caregiving can adversely affect many different aspects of carers’ lives and is widely documented to have a negative impact on carers’ health (mental and physical), economic status and social inclusion, amongst others (e.g. Brown and Mulley, 1997; Henwood, 1998; Keeley and Clarke, 2002). Studies conducted to compare the wellbeing of carers with that of non-carers have found that caregivers often report higher levels of depression and anxiety and greater usage of psychotropic medications than non-carers (Schulz et al., 1995; Schulz & Williamson, 1994). Meanwhile, evidence from India supports an association between poor physical health and carer burden with 50% of mother carers in one study attributing back pain and weight loss to their caring activities (Singhi et al., 1998).

The poor mental health outcomes experienced by carers can be partially understood in light of the widespread social exclusion carers often face. Many carers are tied to the house by their caring responsibilities, unable to attend work or school or to socialise. Caregivers frequently have to curtail their social and leisure activities and a 1967 study by Dupont found that 87% of families reported limiting their cultural interactions with the community due to the stigma of disability. As well as affecting carers’ social interactions in the community, caregiving can also adversely affect relationships within the family, negatively impacting on non-disabled siblings, reducing interaction with other relatives (Jani, 1967) and disrupting family routines and leisure time up by
(particularly if the cared for person frequently needs to visit a community or healthcare centre for treatment) (Gathwala and Gupta, 2004). Furthermore, the huge amount of time and energy taken caring activities often leave carers with little opportunity to explore their own needs and difficulties and can even impact on a carers’ sleep, with one study by Dupont (1967) reporting that 80% of parent carers experienced sleep disturbances. These factors also impact significantly on carers’ mental health.

The challenges of caregiving are further exacerbated by the poor financial situation of many carers. Many carers struggle to find employment that is compatible with their caring duties and thus lose two incomes – that of the affected person and that of the carer who has given up work to care. Furthermore, they must meet the financial needs of their ill or disabled relative as well as meeting the cost of any treatment, often forcing cared for people and their families into significant poverty.

While the vast majority of carers experience some degree of caregiver burden, a number of factors are known to exacerbate this burden.

Some studies suggest that it is not the ‘diagnosis’ of an impairment, but rather the characteristics associated with that diagnosis (e.g. behavioural problems or certain care needs) that are the key predictors of a negative family impact. For example, maladaptive behaviour in disabled children has been associated with increased burden and stress for their parental carers (e.g. Heller, Hsieh, & Rowitz, 1997; Saloviita, Italinna, & Leinonen, 2003; Simmerman, Blacher, & Baker, 2001), poorer parenting efficacy (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006), poorer parental mental health (Herring, Gray, Taffe, Tonge, Sweeney, & Einfeld, 2006) and poorer marital adjustment (Simmerman, Blacher, & Baker, 2001). Similarly, comparative studies of families with and without disabled children found no differences in levels of depression, wellbeing and marital adjustment once behavioural problems were controlled for (Baker, Blacher, and Olsson 2005). Aside from behaviour, other types of care needs can create additional stress and burden for families. Personal care needs (Neely-Barnes & Marcenko, 2004; Warfield, 2001), adaptive behaviour deficits (McCarthy, Cuskelly, van Kraayenoord, & Cohen, 2006; Saloviita, Italinna, & Leinonen, 2003) and certain medical needs (Neely-Barnes & Marcenko, 2004) have been associated with particularly negative family impact, stress, and burden. Thus, research suggests that carer and family outcomes may not be determined simply by the presence or absence of disability, but rather that the presence of certain behaviours and needs associated with an impairment may be far more significant in determining the impact of caring for a disabled family member.

There is also some evidence to suggest that the type of impairment can affect the severity of a carer’s burden with cognitive impairment and mental illness in the care recipient believed to be more burdensome for caregivers than physical impairments due to the magnitude of disruption to family life caused by the caring activities (Dupont, 1967). Differences in the severity of caregiver burden can be found not just between impairment types (e.g. cognitive v. physical impairment), but also within impairment types. Fishman, Woff and Non (1989) found that certain types of intellectual disability affect the level of stress experienced by parents, with parents of autistic children reporting significantly greater levels of stress and depression than parents of children with Down’s syndrome.
Factors external to the disability – such as the amount of time carers must devote to their caregiving duties and the amount of support they receive in their caring activities – are also known to influence caregiver burden. The impact of caregiving on a carer’s mental health becomes greater as the time spent on caregiving increases and although the majority of caregivers provide care gladly, carers with heavier caregiving commitments are more likely to feel negatively about their responsibilities. Goodhead and McDonald (2007) found that caregivers are more positive when they have help from others, a finding supported by a study by Wallander et al. (1989) which found that levels of marital conflict in families with a disabled family member are related to the existence of family support and the presence of a social support network.

Other factors known to affect caregiver burden and/or satisfaction and, in turn, the quality of care provided by carers, include family income, carers’ age, the nature of the relationship between caregiver and care recipient, caregiver attitudes and certain attributes of the care recipient (e.g. age) (Jamuna, 1997), other demands on the caregiver’s time (such as work), the availability of social support and the health status of the caregiver (Jamuna and Ramamurthi, 1999).

An important dimension of caregiving that deserves particular attention is its gendered nature. As many as 80% of unpaid family carers worldwide are female, yet due to gender discrimination their contributions often go unrecognised and they frequently remain unsupported by policy makers and governments. Evidence from India indicates that traditionally caregiving falls to women (Prakash, 2001, 1999), especially in rural communities (Jamuna, 1997; Chakrabarti, 1999; Sharma, 2003). Furthermore, female carers have been found to be impacted differently by caregiving than men and to experience a more acute burden of care. For example, a study by Dupont (1967) found that mother carers scored significantly more highly on scales of anxiety and depression, than fathers.

Heller, Hsieh and Rowitz (1997) shed some light on these gender differences in a study of parental carers of children with learning disabilities, explaining that mothers of disabled children spend more time providing care and offer a greater range of support to the child than fathers and therefore the behaviour and health of the child has a greater impact on mothers. Further explanation of these gender differences is provided by Peshawaria et al. (1998) who report that in India gender plays a role in enabling or inhibiting the factors that affect a parent’s ability to cope, citing the example of mothers whose proscribed social role puts them under greater pressure to balance the needs of the person they care for with their household duties. Moreover, women are often engaged in providing care to two generations simultaneously – rearing their own children and providing long-term care to elderly relatives -with significant costs to both their physical and psychological wellbeing (Prakash, 1999; Hirst, 2005). As a result of these gender differences, significantly fewer women express satisfaction about their caring role than men (Prasad and Rani, 2007). Even amongst female carers there is a hierarchy of care which results in some female carers experiencing a much greater burden of care than others. Where the care recipient is male, care most commonly falls to wives and then to daughters-in-law, whereas when the care recipient is female, providing care is the responsibility of daughters-in-law in the first instance and then of daughters (Prakash, 1999; Sharma, 2003). Amongst female caregivers, daughters-in-law reported the highest stress levels, followed by spouses and daughters (Jamuna, 1997).
## Baseline study results

A total of 1540 carers and the people they care for were surveyed to form this baseline study. Participants came from three different areas, where our partner organisations – NBJK, SAMUHA and SACRED – were already working to support disabled people and were looking to expand their work to support carers too.

## Profile of caregivers

### Age

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Total (n=1540)</th>
<th>NBJK (n = 860)</th>
<th>SAMUHA (n = 180)</th>
<th>SACRED (n = 500)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-10</td>
<td>0.2% (n = 3)</td>
<td>0.3% (n = 3)</td>
<td>0.0% (n = 0)</td>
<td>0.0% (n = 0)</td>
</tr>
<tr>
<td>11-20</td>
<td>2.6% (n = 40)</td>
<td>2.7% (n = 23)</td>
<td>2.2% (n = 4)</td>
<td>2.6% (n = 13)</td>
</tr>
<tr>
<td>21-30</td>
<td>25.0% (n = 385)</td>
<td>23.0% (n = 198)</td>
<td>47.8% (n = 86)</td>
<td>20.2% (n = 101)</td>
</tr>
<tr>
<td>31-40</td>
<td>30.8% (n = 475)</td>
<td>30.0% (n = 258)</td>
<td>27.2% (n = 49)</td>
<td>33.6% (n = 168)</td>
</tr>
<tr>
<td>41-50</td>
<td>26.4% (n = 406)</td>
<td>28.7% (n = 247)</td>
<td>12.2% (n = 22)</td>
<td>27.4% (n = 137)</td>
</tr>
<tr>
<td>51-60</td>
<td>11.6% (n = 178)</td>
<td>11.5% (n = 99)</td>
<td>6.1% (n = 11)</td>
<td>13.6% (n = 68)</td>
</tr>
<tr>
<td>61-70</td>
<td>2.9% (n = 44)</td>
<td>2.9% (n = 25)</td>
<td>3.9% (n = 7)</td>
<td>2.4% (n = 12)</td>
</tr>
<tr>
<td>71-80</td>
<td>0.5% (n = 8)</td>
<td>0.7% (n = 6)</td>
<td>0.6% (n = 1)</td>
<td>0.2% (n = 1)</td>
</tr>
<tr>
<td>81-90</td>
<td>0.1% (n = 1)</td>
<td>0.1% (n = 1)</td>
<td>0.0% (n = 0)</td>
<td>0.0% (n = 0)</td>
</tr>
</tbody>
</table>
With the exception of a small minority of child carers (approx. 2.8%), 97.2% of carers in all project areas are adults. The vast majority of carers (82.2%) are aged between 20 and 50, a trend that is consistent in all project areas, though in SAMUHA’s project area there is a much higher percentage of younger carers (47.8% aged 21-30) than NBJK (23.0%) and SACRED (20.2%). Numbers of elderly carers (61+) are low in all areas and represent just 3.5% of carers overall.
Across all project areas, carers are predominantly women (84.3%). Even in the project area with the lowest proportion of women carers (SACRED), ¾ of carers are women (75.4%) and in SAMUHA’s project area, as many as 9 out of every 10 carers (91.1%) are women.
The overwhelming majority (94.0%) of carers in all project areas are married. In SAMUHA and SACRED’s project areas the percentage of single carers is as low as 2.2% and 1.2% respectively. Although this figure rises to 9.7% for NBJK carers, marriage is still by far the dominant relationship status for carers.
**Family type**

<table>
<thead>
<tr>
<th></th>
<th>TOTAL (n = 1540)</th>
<th>NBJK (n = 860)</th>
<th>SAMUHA (n = 180)</th>
<th>SACRED (n = 500)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Joint</strong>*</td>
<td>37.3% (n = 575)</td>
<td>43.6% (n = 375)</td>
<td>27.2% (n = 49)</td>
<td>30.2% (n = 151)</td>
</tr>
<tr>
<td><strong>Nuclear</strong>**</td>
<td>63.7% (n = 965)</td>
<td>56.4% (n = 485)</td>
<td>72.8% (n = 131)</td>
<td>69.8% (n = 349)</td>
</tr>
</tbody>
</table>

* including extended family and merged family units
** immediate family only

Carers predominantly come from nuclear families (62.7%), though a significant proportion (37.3%) come from joint families. The split between nuclear and joint families is more pronounced in SAMUHA and SACRED project areas, with nuclear families being more dominant (72.8% and 69.8% respectively) than joint families. Meanwhile in NBJK’s project area there is a more even split between family types (56.4% nuclear, 43.6% joint).
Number of household members

<table>
<thead>
<tr>
<th>TOTAL (n = 1540)</th>
<th>NBJK (n = 860)</th>
<th>SAMUHA (n = 180)</th>
<th>SACRED (n = 500)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1-5</strong></td>
<td>53.4% (n = 823)</td>
<td>44.3% (n = 381)</td>
<td>53.9% (n = 97)</td>
</tr>
<tr>
<td><strong>6-10</strong></td>
<td>40.8% (n = 629)</td>
<td>48.0% (n = 413)</td>
<td>36.1% (n = 65)</td>
</tr>
<tr>
<td><strong>11-15</strong></td>
<td>4.5% (n = 69)</td>
<td>6.2% (n = 53)</td>
<td>6.7% (n = 12)</td>
</tr>
<tr>
<td><strong>16-20</strong></td>
<td>0.9% (n = 14)</td>
<td>1.0% (n = 9)</td>
<td>2.8% (n = 5)</td>
</tr>
<tr>
<td><strong>21-25</strong></td>
<td>0.3% (n = 4)</td>
<td>0.5% (n = 4)</td>
<td>0.0% (n = 0)</td>
</tr>
<tr>
<td><strong>26-30</strong></td>
<td>0.1% (n = 1)</td>
<td>0.0% (n = 0)</td>
<td>0.6% (n = 1)</td>
</tr>
</tbody>
</table>

On the whole, the overwhelming majority of carer families (94.2%) have 10 or fewer family members, though a small but significant percentage of NBJK (7.7%) and SAMUHA (10.0%) carers come from larger families of 11+ family members. Overall, carer families in NBJK’s project area are larger than in SAMUHA and SACRED’s project areas, with a larger proportion of families of 6-10 members (48.0%) than SAMUHA (36.1%) and SACRED (30.2%).
### Number of male household members

<table>
<thead>
<tr>
<th></th>
<th>TOTAL</th>
<th>NBJK</th>
<th>SAMUHA</th>
<th>SACRED</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n = 1540)</td>
<td>(n = 860)</td>
<td>(n = 180)</td>
<td>(n = 500)</td>
</tr>
<tr>
<td>0-5</td>
<td>96.4% (n = 1484)</td>
<td>94.1% (n = 809)</td>
<td>97.8% (n = 176)</td>
<td>99.8% (n = 499)</td>
</tr>
<tr>
<td>6-10</td>
<td>3.5% (n = 54)</td>
<td>5.7% (n = 49)</td>
<td>2.2% (n = 4)</td>
<td>0.2% (n = 1)</td>
</tr>
<tr>
<td>11-15</td>
<td>0.1% (n = 1)</td>
<td>0.1% (n = 1)</td>
<td>0.0% (n = 0)</td>
<td>0.0% (n = 0)</td>
</tr>
<tr>
<td>16-20</td>
<td>0.1% (n = 1)</td>
<td>0.1% (n = 1)</td>
<td>0.0% (n = 0)</td>
<td>0.0% (n = 0)</td>
</tr>
</tbody>
</table>

Few carer families have more than 5 male family members (3.6%). The slightly higher incidence of 6 or more male family members in NBJK’s project area might reflect the larger average family sizes of NBJK carers in general and the increased prevalence of joint families.
Few carer families have more than 5 female family members (7.0%). Indeed in SACRED’s project area there are no families at all with more than 5 female family members. In NBJK’s project area, a small, but significant number of families (12.0%) have more than 5 female family members, which might reflect the fact that carer families are larger in NBJK areas in general and are more likely to be joint families.
### Number of child household members

<table>
<thead>
<tr>
<th></th>
<th>TOTAL (n = 1540)</th>
<th>NBJK (n = 860)</th>
<th>SAMUHA (n = 180)</th>
<th>SACRED (n = 500)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-5</td>
<td>97.9% (n = 1508)</td>
<td>97.3% (n = 837)</td>
<td>95.0% (n = 171)</td>
<td>100.0% (n = 500)</td>
</tr>
<tr>
<td>6-10</td>
<td>1.9% (n = 29)</td>
<td>2.6% (n = 22)</td>
<td>3.9% (n = 7)</td>
<td>0.0% (n = 0)</td>
</tr>
<tr>
<td>11-15</td>
<td>0.2% (n = 3)</td>
<td>0.1% (n = 1)</td>
<td>1.1% (n = 2)</td>
<td>0.0% (n = 0)</td>
</tr>
</tbody>
</table>

Few carer families have more than 5 children (2.1%). Indeed, no SACRED carers come from families with more than 5 children. While a small proportion of carer families have more than 5 child family members (2.6% for NBJK, 3.9% for SAMUHA), only 3 families in total across all partners have 11 or more children.
Relationship with care recipient

<table>
<thead>
<tr>
<th>Relationship with</th>
<th>TOTAL (n = 1540)</th>
<th>NBJK (n = 860)</th>
<th>SAMUHA (n = 180)</th>
<th>SACRED (n = 500)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Father</td>
<td>6.6% (n = 102)</td>
<td>6.4% (n = 42)</td>
<td>0.6% (n = 1)</td>
<td>11.8% (n = 59)</td>
</tr>
<tr>
<td>Mother</td>
<td>45.7% (n = 704)</td>
<td>71.2% (n = 470)</td>
<td>0.6% (n = 1)</td>
<td>46.6% (n = 233)</td>
</tr>
<tr>
<td>Spouse</td>
<td>26.8% (n = 441)</td>
<td>14.8% (n = 98)</td>
<td>2.8% (n = 5)</td>
<td>27.6% (n = 138)</td>
</tr>
<tr>
<td>Child</td>
<td>12.3% (n = 189)</td>
<td>3.2% (n = 21)</td>
<td>88.3% (n = 159)</td>
<td>1.8% (n = 9)</td>
</tr>
<tr>
<td>Other</td>
<td>6.8% (n = 104)</td>
<td>4.4% (n = 29)</td>
<td>7.8% (n = 14)</td>
<td>12.2% (n = 61)</td>
</tr>
</tbody>
</table>

Overall, more care recipients are cared for by their mothers than by any other relative (45.7%) and this trend is particularly strong among NBJK carers, of whom 71.2% are mothers. However in SAMUHA’s project area, the vast majority of caregiving is performed by the care recipients’ sons and daughters (88.3%). A small but significant percentage of care is performed by fathers in both NBJK (6.4%) and SACRED (11.8%) areas, though only one father is a caregiver in SAMUHA’s project area. Similarly, spouses represent an important source of care in NBJK (14.8%) and SACRED (27.6%) project areas, but play a much smaller role in SAMUHA’s project area (2.8%).
Educational status of caregivers

41% of carers have received some form of education, though there are significant differences between the partners. While NBJK and SAMUHA have comparable numbers of carers with some level of education (47%), only 17% of SACRED carers have received any formal education.

Amongst those carers who are educated, levels of primary and secondary education are less consistent. More NBJK carers have achieved secondary education (31.7%) than primary education alone (13.4%), while SAMUHA and SACRED carers are more likely to have completed just primary education (31.7% and 11.6% respectively) rather than secondary education (16.7% and 4.8% respectively). Levels of tertiary (college) education are low for all partners. Additionally, a handful of carers from NBJK (n = 5) and SAMUHA (n = 2) report that they are still pursuing education.
The majority of carers are unemployed (60.5%), though this varies significantly according to the different project areas. Unemployment amongst NBJK carers is very high at 86.5%, with only 13.5% of carers in some form of employment. However this situation is almost entirely reversed in SACRED’s project areas, with carer employment rates as high as 83.2% and unemployment at just 16.8%. Meanwhile, in SAMUHA’s project area, the balance between unemployed and employed carers is much more even (42.8% and 57.2% respectively).
The 609 carers in employment work across a wide-range of professions. The majority of carers have practical vocational skills and are primarily engaged in handicrafts, skilled labour, tertiary services or agricultural work. Types of employment reported by carers include:

<table>
<thead>
<tr>
<th>Agriculture</th>
<th>Dhobi¹</th>
<th>Selling home-made products</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anganbari sahayaka²</td>
<td>Driving</td>
<td>Selling jewellery</td>
</tr>
<tr>
<td>Anganwadi teachers³</td>
<td>Miller</td>
<td>Selling milk</td>
</tr>
<tr>
<td>Animal husbandry</td>
<td>Hairdressing</td>
<td>Selling vegetables</td>
</tr>
<tr>
<td>Book keeping</td>
<td>Hotel staff</td>
<td>Shopkeeper</td>
</tr>
<tr>
<td>Carpentry</td>
<td>Making brooms</td>
<td>Silk weaving</td>
</tr>
<tr>
<td>Casual labouring</td>
<td>Making ice cream</td>
<td>Small business</td>
</tr>
<tr>
<td>Cooking</td>
<td>Making medicine packets</td>
<td>Tailoring</td>
</tr>
<tr>
<td>Computer operator</td>
<td>Pottery</td>
<td>Tea vendor</td>
</tr>
<tr>
<td>Data operators</td>
<td>Selling flowers</td>
<td>Teaching</td>
</tr>
</tbody>
</table>

¹ Laundry woman
² Assistant in state-provided preschool provision
³ Teacher in state-provided preschool provision
Of those carers who do not work, just under a third (29%) are prevented from doing so because they are unable to find someone else to cover their caring responsibilities, though this varies greatly between the partners. For example, a lack of alternative care arrangements is the overwhelming reason (70.9%) that SAMUHA carers don’t work, yet in NBJK’s project area the lack of available work (34%) and other unspecified factors (43%) have a much greater impact on carer employment levels than a lack of alternative care arrangements (22%). Nevertheless, it is possible that the health problems and other unidentified factors which prevent carers from working may also be related – either directly or indirectly – to their caring activities.
The majority of carers (62.3%) report having no income at all, though this figure masks significant variation between partners. In NBJK’s project area the financial situation of carers is particularly stark, with 89.4% reporting no sources of income at all. Although the situation is less acute in SAMUHA’s project area, more than half of carers (57.2%) still have no source of income. Interestingly, of those SAMUHA who do have a source of income, more carers earn a mid-level income (27.2%) than earn a lower income (10.0%) or higher income (5.6%). SACRED’s carers reverse the overall trend, with the lowest proportion of carers with no income (17.4%) or low income (31.0%) and the highest proportion of carers earning mid-level incomes (47.2%).

### Carer income per month

<table>
<thead>
<tr>
<th>Income per month (Indian Rupees)</th>
<th>TOTAL (n = 1540)</th>
<th>NBJK (n = 860)</th>
<th>SAMUHA (n = 180)</th>
<th>SACRED (n = 500)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 INR</td>
<td>62.3% (n = 959)</td>
<td>89.4% (n = 769)</td>
<td>57.2% (n = 103)</td>
<td>17.4% (n = 87)</td>
</tr>
<tr>
<td>0-1000 INR</td>
<td>11.9% (n = 183)</td>
<td>1.2% (n = 10)</td>
<td>10.0% (n = 18)</td>
<td>31.0% (n = 155)</td>
</tr>
<tr>
<td>1000-3000 INR</td>
<td>22.9% (n = 353)</td>
<td>7.9% (n = 68)</td>
<td>27.2% (n = 49)</td>
<td>47.2% (n = 236)</td>
</tr>
<tr>
<td>3000-6000 INR</td>
<td>2.9% (n = 45)</td>
<td>1.5% (n = 13)</td>
<td>5.6% (n = 10)</td>
<td>4.4% (n = 22)</td>
</tr>
<tr>
<td>Source of Income</td>
<td>TOTAL (n = 797)</td>
<td>NBJK (n = 491)</td>
<td>SAMUHA (n = 132)</td>
<td>SACRED (n = 174)</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>-----------------</td>
<td>----------------</td>
<td>------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Disability pension (DP)</td>
<td>69.3% (n = 552)</td>
<td>60.1% (n = 295)</td>
<td>78.8% (n = 104)</td>
<td>87.9% (n = 153)</td>
</tr>
<tr>
<td>Old age pension (OAP)</td>
<td>2.9% (n = 23)</td>
<td>2.2% (n = 11)</td>
<td>5.3% (n = 7)</td>
<td>2.9% (n = 5)</td>
</tr>
<tr>
<td>Retirement pension (RP)</td>
<td>0.8% (n = 6)</td>
<td>1.2% (n = 6)</td>
<td>0% (n = 0)</td>
<td>0% (n = 0)</td>
</tr>
<tr>
<td>Widows’ pension (WP)</td>
<td>2.6% (n = 21)</td>
<td>0.6% (n = 3)</td>
<td>1.5% (n = 2)</td>
<td>9.2% (n = 16)</td>
</tr>
<tr>
<td>Income from property</td>
<td>1.5% (n = 12)</td>
<td>2.4% (n = 12)</td>
<td>0% (n = 0)</td>
<td>0% (n = 0)</td>
</tr>
<tr>
<td>Other</td>
<td>20.6% (n = 164)</td>
<td>33.4% (n = 164)</td>
<td>0% (n = 0)</td>
<td>0% (n = 0)</td>
</tr>
<tr>
<td>Disability pension + old age pension</td>
<td>1.5% (n = 12)</td>
<td>0% (n = 0)</td>
<td>9.1% (n = 12)</td>
<td>0% (n = 0)</td>
</tr>
<tr>
<td>Disability pension + widows’ pension</td>
<td>0.6% (n = 5)</td>
<td>0% (n = 0)</td>
<td>3.8% (n = 5)</td>
<td>0% (n = 0)</td>
</tr>
<tr>
<td>Disability pension + widows’ pension + old age pension</td>
<td>0.1% (n = 1)</td>
<td>0% (n = 0)</td>
<td>0.8% (n = 1)</td>
<td>0% (n = 0)</td>
</tr>
<tr>
<td>Disability pension + old age pension + other</td>
<td>0.1% (n = 1)</td>
<td>0% (n = 0)</td>
<td>0.5% (n = 1)</td>
<td>0% (n = 0)</td>
</tr>
</tbody>
</table>
A number of carers (51.7%) report extra sources of income in addition to their employment or income-generating activities. SAMUHA carers are most likely to have an additional source of income (73.3%) while SACRED carers are least likely to have any additional income sources (34.8%). Meanwhile, just over half of NBJK carers access extra sources of income (57.1%).

The most common source of additional income for carers’ households is the disability pension awarded to the person they care for. This pension is received by the majority of carers across all project areas (69.3%). The only other source of income accessed consistently across all project areas (though by a much smaller number of carers) is the old age pension (overall = 2.9%). Although not claimed by many NBJK or SAMUHA carers, a small but significant number of SACRED carers claim a widows’ pension (9.2%).
Only a few carers have taken out loans overall (14.0%). NBJK has the lowest number of carers who have taken out loans (11.6%) while SAMUHA have the greatest proportion of carers taking out loans (25.0%).
### Source of loan

<table>
<thead>
<tr>
<th>Source</th>
<th>Total: (n=215)</th>
<th>NBJK (n=100)</th>
<th>SAMUHA (n=45)</th>
<th>SACRED (n=70)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers project</td>
<td>7.0% (n=15)</td>
<td>0.0% (n=0)</td>
<td>0.0% (n=0)</td>
<td>21.4% (n=15)</td>
</tr>
<tr>
<td>Bank</td>
<td>36.3% (n=78)</td>
<td>11.0% (n=11)</td>
<td>40.0% (n=18)</td>
<td>70.0% (n=49)</td>
</tr>
<tr>
<td>Government scheme</td>
<td>12.6% (n=27)</td>
<td>27.0% (n=27)</td>
<td>0.0% (n=0)</td>
<td>0.0% (n=0)</td>
</tr>
<tr>
<td>Other</td>
<td>44.2% (n=95)</td>
<td>62.0% (n=62)</td>
<td>60.0% (n=27)</td>
<td>8.6% (n=6)</td>
</tr>
</tbody>
</table>

The size of loans to be repaid by the 215 carers with loans, ranges from 1,000 INR to 50,000 INR. 82 carers must repay smaller loans of up to 10,000 INR and 89 must repay mid-level loans of between 10,000 INR – 20,000 INR. A further 46 carers are due to repay larger loans between 20,000 INR and 50,000 INR.
A number of carers have identified skills which might offer the opportunity to generate additional income. Overall 48% of carers report having a skill which they could use to generate a source of income (respectively 53% from NBJK, 30% from SAMUHA and 44% from SACRED. Most carers reporting income generation skills are skilled in various handicraft activities, with a significant number also skilled in agricultural work and animal husbandry. In SACRED’s project area, by far the most common skills amongst carers is the production of agarbathi (incense). Skills cited by carers include:

<table>
<thead>
<tr>
<th>Agarbathi production</th>
<th>Embroidery</th>
<th>Rope making</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agriculture</td>
<td>Goldsmithing</td>
<td>Pot making</td>
</tr>
<tr>
<td>Animal husbandry</td>
<td>Hairdressing</td>
<td>Polish cutting</td>
</tr>
<tr>
<td>Bag making</td>
<td>Handicrafts</td>
<td>Silk weaving</td>
</tr>
<tr>
<td>Basket making</td>
<td>Mat and rope making</td>
<td>Sweater knitting</td>
</tr>
<tr>
<td>Driving</td>
<td>Making medicine packets</td>
<td>Tailoring</td>
</tr>
<tr>
<td>Electrician</td>
<td>‘Other’</td>
<td></td>
</tr>
</tbody>
</table>
27% of carers surveyed report having health problems, though rates of ill health are significantly higher amongst SACRED carers (44%) and significantly lower for SAMUHA carers (11%). Further research is needed to understand whether this ill health relates to the carers’ caring activities and how it compares to rates of ill health amongst non-carers. Some carers receive treatment at government hospitals, but others remain untreated due to financial constraints or due to the burden of their caregiving responsibilities. For example, of the 219 carers from SACRED who report health problems, 96 remain untreated as they cannot afford to pay for treatment, while a further 28 are unable to access treatment due to the burden of their caring activities. Meanwhile only 9 of the 19 SAMUHA carers reporting health concerns have received treatment, with the remaining 10 citing a lack of financial resources for their lack of treatment. Health issues reported by carers include the following:
Carer membership of self-help groups

<table>
<thead>
<tr>
<th>Condition</th>
<th>Total: (n=1540)</th>
<th>NBJK (n = 860)</th>
<th>SAMUHA (n = 180)</th>
<th>SACRED (n = 500)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Member of self-help group</td>
<td>45.5% (n = 701)</td>
<td>45.3% (n = 390)</td>
<td>55.0% (n = 99)</td>
<td>42.4% (n = 212)</td>
</tr>
<tr>
<td>Not member of self-help group</td>
<td>54.5% (n = 839)</td>
<td>54.7% (n = 470)</td>
<td>45.0% (n = 81)</td>
<td>57.6% (n = 288)</td>
</tr>
</tbody>
</table>

Just under half (45.5%) of all carers are members of some kind of self-help group within their community. The picture is similar across all 3 project partners, although amongst SAMUHA carers this trend is reversed, with just over half (55.0%) of carers members of some kind of self-help group.
Only a small number of carers (10.9%) are members of any community groups (other than self-help groups – see above). While this number is higher for SAMUHA carers, of whom 25.0% are members of community groups, in SACRED’s project area, just 3 carers are members of any community groups.
## Profile of care recipients

### Age

<table>
<thead>
<tr>
<th></th>
<th>Total (n=1540)</th>
<th>NBJK (n = 860)</th>
<th>SAMUHA (n = 180)</th>
<th>SACRED (n = 500)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-10</td>
<td>18.6% (n = 286)</td>
<td>12.6% (n = 108)</td>
<td>62.8% (n = 113)</td>
<td>13.0% (n = 65)</td>
</tr>
<tr>
<td>11-20</td>
<td>27.1% (n = 417)</td>
<td>29.0% (n = 249)</td>
<td>21.7% (n = 39)</td>
<td>25.8% (n = 129)</td>
</tr>
<tr>
<td>21-30</td>
<td>20.0% (n = 308)</td>
<td>21.4% (n = 184)</td>
<td>5.6% (n = 10)</td>
<td>22.8% (n = 114)</td>
</tr>
<tr>
<td>31-40</td>
<td>14.5% (n = 223)</td>
<td>14.5% (n = 125)</td>
<td>4.4% (n = 8)</td>
<td>18.0% (n = 90)</td>
</tr>
<tr>
<td>41-50</td>
<td>10.6% (n = 164)</td>
<td>11.3% (n = 97)</td>
<td>3.9% (n = 7)</td>
<td>12.0% (n = 60)</td>
</tr>
<tr>
<td>51-60</td>
<td>5.3% (n = 81)</td>
<td>6.2% (n = 53)</td>
<td>1.1% (n = 2)</td>
<td>5.2% (n = 26)</td>
</tr>
<tr>
<td>61-70</td>
<td>3.4% (n = 52)</td>
<td>4.1% (n = 35)</td>
<td>0.6% (n = 1)</td>
<td>3.2% (n = 16)</td>
</tr>
<tr>
<td>71-80</td>
<td>0.4% (n = 6)</td>
<td>0.7% (n = 6)</td>
<td>0% (n = 0)</td>
<td>0% (n = 0)</td>
</tr>
<tr>
<td>81-90</td>
<td>0.2% (n = 3)</td>
<td>0.3% (n = 3)</td>
<td>0% (n = 0)</td>
<td>0% (n = 0)</td>
</tr>
</tbody>
</table>
Care recipients are predominantly fairly young, with 80.2% of care recipients aged 40 or younger, although there is a good representation of care recipients across all age groups. In SAMUHA’s project area the majority of care recipients (62.8%) are aged 10 or younger.
A similar ratio of male to female care recipients can be seen across all project areas (60.8% male to 39.2% female), with little variation amongst partners.
## Impairment type

<table>
<thead>
<tr>
<th>Impairment Type</th>
<th>Total (n = 1540)</th>
<th>NBJK (n = 860)</th>
<th>SAMUHA (n = 180)</th>
<th>SACRED (n = 500)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cerebral palsy</td>
<td>11.5% (n = 177)</td>
<td>7.6% (n = 65)</td>
<td>41.1% (n = 74)</td>
<td>7.6% (n = 38)</td>
</tr>
<tr>
<td>Learning disability</td>
<td>30.0% (n = 462)</td>
<td>26.2% (n = 225)</td>
<td>36.7% (n = 66)</td>
<td>27.4% (n = 137)</td>
</tr>
<tr>
<td>Mental illness</td>
<td>8.5% (n = 131)</td>
<td>11.3% (n = 97)</td>
<td>5.0% (n = 9)</td>
<td>5.0% (n = 25)</td>
</tr>
<tr>
<td>Physical impairment</td>
<td>14.4% (n = 222)</td>
<td>23.3% (n = 200)</td>
<td>3.9% (n = 7)</td>
<td>44.4% (n = 222)</td>
</tr>
<tr>
<td>Speech/hearing impairment</td>
<td>4.2% (n = 65)</td>
<td>2.1% (n = 18)</td>
<td>1.7% (n = 3)</td>
<td>8.8% (n = 44)</td>
</tr>
<tr>
<td>Visual impairment</td>
<td>6.6% (n = 102)</td>
<td>7.8% (n = 67)</td>
<td>0.6% (n = 1)</td>
<td>6.8% (n = 34)</td>
</tr>
<tr>
<td>Other</td>
<td>24.7% (n = 381)</td>
<td>21.9% (n = 188)</td>
<td>11.1% (n = 20)</td>
<td>0% (n = 0)</td>
</tr>
</tbody>
</table>

### TOTAL

- Cerebral Palsy: 11.5%
- Learning disability: 30.0%
- Mental illness: 8.5%
- Physical impairment: 14.4%
- Speech/hearing impairment: 4.2%
- Visual impairment: 6.6%
- Other: 24.7%

### NBKJ

- Cerebral Palsy: 7.6%
- Learning disability: 21.9%
- Mental illness: 11.3%
- Physical impairment: 23.3%
- Speech/hearing impairment: 26.2%
- Visual impairment: 7.8%
- Other: 2.1%

### SAMUHA

- Cerebral Palsy: 3.9%
- Learning disability: 11.1%
- Mental illness: 5.0%
- Physical impairment: 41.1%
- Speech/hearing impairment: 36.7%
- Visual impairment: 0.6%
- Other: 8.8%

### SACRED

- Cerebral Palsy: 8.8%
- Learning disability: 27.4%
- Mental illness: 6.8%
- Physical impairment: 44.4%
- Speech/hearing impairment: 5.0%
- Visual impairment: 7.6%
- Other: 0%
There is a wide range of impairments and a wide variation in their distribution in different project areas. While cerebral palsy is present amongst a small number of care recipients in NBJK and SACRED project areas (both 7.6%), it is the most commonly reported impairment for SAMUHA care recipients (41.1%). Learning disabilities are also common in all project areas with fairly similar prevalence of 26.2% (NBJK), 36.7% (SAMUHA) and 27.4% (SACRED) reported. While physical impairments represent a significant proportion of impairments amongst care recipients in NBJK’s project area (23.3%) and are the most prevalent impairment amongst care recipients in SACRED’s project area (44.4%), there are very few care recipients with physical impairments in SAMUHA’s project area (3.9%). Mental illness represents a small but significant proportion of impairments for each partner (11.3% for NBJK, 5.0% for SAMUHA, 5.0% for SACRED).

### Duration of impairment

<table>
<thead>
<tr>
<th></th>
<th>Total (n=1540)</th>
<th>NBJK (n = 860)</th>
<th>SAMUHA (n = 180)</th>
<th>SACRED (n = 500)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-10</td>
<td>32.5% (n = 501)</td>
<td>32.2% (n = 277)</td>
<td>65.0% (n = 117)</td>
<td>21.4% (n = 107)</td>
</tr>
<tr>
<td>11-20</td>
<td>32.5% (n = 501)</td>
<td>32.8% (n = 282)</td>
<td>25.0% (n = 45)</td>
<td>34.8% (n = 174)</td>
</tr>
<tr>
<td>21-30</td>
<td>18.6% (n = 286)</td>
<td>18.3% (n = 157)</td>
<td>6.7% (n = 12)</td>
<td>23.4% (n = 117)</td>
</tr>
<tr>
<td>31-40</td>
<td>8.7% (n = 134)</td>
<td>9.1% (n = 78)</td>
<td>2.8% (n = 5)</td>
<td>10.2% (n = 51)</td>
</tr>
<tr>
<td>41-50</td>
<td>4.4% (n = 67)</td>
<td>4.4% (n = 38)</td>
<td>0.0% (n = 0)</td>
<td>5.8% (n = 29)</td>
</tr>
<tr>
<td>51-60</td>
<td>2.1% (n = 33)</td>
<td>1.7% (n = 15)</td>
<td>0.0% (n = 0)</td>
<td>3.6% (n = 18)</td>
</tr>
<tr>
<td>61-70</td>
<td>0.8% (n = 12)</td>
<td>1.0% (n = 9)</td>
<td>0.0% (n = 0)</td>
<td>0.6% (n = 3)</td>
</tr>
<tr>
<td>71-80</td>
<td>0.0% (n = 0)</td>
<td>0.0% (n = 0)</td>
<td>0.0% (n = 0)</td>
<td>0.0% (n = 0)</td>
</tr>
<tr>
<td>81-90</td>
<td>0.1% (n = 1)</td>
<td>0.1% (n = 1)</td>
<td>0.0% (n = 0)</td>
<td>0.0% (n = 0)</td>
</tr>
<tr>
<td>Unknown</td>
<td>0.3% (n = 5)</td>
<td>0.3% (n = 3)</td>
<td>0.6% (n = 1)</td>
<td>0.2% (n = 1)</td>
</tr>
</tbody>
</table>
The majority of care recipients have lived with their impairment for between 1 and 20 years (65%), though a significant number have lived with their impairment for more than 20 years (35%) and some for more than 50 years (3.3%). On the whole care recipients in SAMUHA’s project area have lived with their impairment for less time than care recipients in NBJK’s and SACRED’s project areas, with 65.0% of carers living with impairment for 10 years or fewer.
Care recipient livelihoods

<table>
<thead>
<tr>
<th></th>
<th>TOTAL (n=1540)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>8.4% (n = 130)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>91.6% (n = 1410)</td>
</tr>
</tbody>
</table>

The 130 care recipients in employment work across a wide range of professions, as detailed below. In these roles, care recipients earned between IRS 100 and IRS 20,000 per month.

<table>
<thead>
<tr>
<th>Agricultural labour</th>
<th>Miller</th>
<th>Small shop</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barber</td>
<td>Gopala mithra&lt;sup&gt;5&lt;/sup&gt;</td>
<td>Community development</td>
</tr>
<tr>
<td>Blacksmith</td>
<td>Hotel staff</td>
<td>Tailoring</td>
</tr>
<tr>
<td>Casual labourer</td>
<td>Lorry driver</td>
<td>Tea vendor</td>
</tr>
<tr>
<td>Chicken farmer</td>
<td>Mobile business</td>
<td></td>
</tr>
<tr>
<td>Driver</td>
<td>NREGA worker&lt;sup&gt;6&lt;/sup&gt;</td>
<td></td>
</tr>
</tbody>
</table>

<sup>5</sup> Cowherd
<sup>6</sup> Employee in government scheme that guarantees 100 days of work (typically manual labour) per year to those without an income, under the National Rural Employment Guarantee Act
A significant number (41.2%) of all care recipients are members of some kind of self-help group within their community, although the majority (58.8%) of care recipients do not currently benefit from membership of a self-help group.
Measuring carer wellbeing

Concerns about personal life

<table>
<thead>
<tr>
<th>Questions</th>
<th>Variable</th>
<th>TOTAL (n = 1540)</th>
<th>NBJK (n = 860)</th>
<th>SAMUHA (n = 180)</th>
<th>SACRED (n = 500)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How concerned are you about:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A. not having enough time to yourself?</td>
<td>A lot</td>
<td>429</td>
<td>359</td>
<td>15</td>
<td>55</td>
</tr>
<tr>
<td></td>
<td>Quite a bit</td>
<td>679</td>
<td>422</td>
<td>87</td>
<td>170</td>
</tr>
<tr>
<td></td>
<td>Little</td>
<td>301</td>
<td>64</td>
<td>64</td>
<td>173</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>131</td>
<td>15</td>
<td>14</td>
<td>102</td>
</tr>
<tr>
<td>B. not being able to take a break from caring?</td>
<td>A lot</td>
<td>268</td>
<td>186</td>
<td>22</td>
<td>60</td>
</tr>
<tr>
<td></td>
<td>Quite a bit</td>
<td>719</td>
<td>507</td>
<td>89</td>
<td>123</td>
</tr>
<tr>
<td></td>
<td>Little</td>
<td>417</td>
<td>133</td>
<td>66</td>
<td>218</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>136</td>
<td>34</td>
<td>03</td>
<td>99</td>
</tr>
<tr>
<td>C. not being able to plan for the future?</td>
<td>A lot</td>
<td>265</td>
<td>180</td>
<td>12</td>
<td>73</td>
</tr>
<tr>
<td></td>
<td>Quite a bit</td>
<td>495</td>
<td>302</td>
<td>87</td>
<td>106</td>
</tr>
<tr>
<td></td>
<td>Little</td>
<td>509</td>
<td>220</td>
<td>81</td>
<td>208</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>271</td>
<td>158</td>
<td>0</td>
<td>113</td>
</tr>
<tr>
<td>D. not being able to continue caring (e.g. because you are ill yourself)?</td>
<td>A lot</td>
<td>174</td>
<td>60</td>
<td>8</td>
<td>106</td>
</tr>
<tr>
<td></td>
<td>Quite a bit</td>
<td>426</td>
<td>226</td>
<td>81</td>
<td>119</td>
</tr>
<tr>
<td></td>
<td>Little</td>
<td>429</td>
<td>182</td>
<td>91</td>
<td>156</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>511</td>
<td>392</td>
<td>0</td>
<td>119</td>
</tr>
</tbody>
</table>

![Bar chart](image)
Carers’ greatest concerns about the impact of caring on their personal life are centred around them not having enough time for themselves (71.9% reporting ‘a lot’ or ‘quite a bit’ of concern) and not being able to take a break from their caring duties (64.1% reporting ‘a lot’ or ‘quite a bit’ of concern). Worries about not being able to plan for the future or fears about not being able to continue with their caring activities are also concerns for a number of carers, but prompt less anxiety (49.3% and 39.0% respectively reporting ‘a lot’ or ‘quite a bit’ of concern) than other concerns. Carers from NBJK’s project areas express higher levels of anxiety, while SACRED carers from report fewer worries about the impact of caring on their personal life, across the board.

Concerns about relationships

<table>
<thead>
<tr>
<th>Questions</th>
<th>Variable</th>
<th>TOTAL (n = 1540)</th>
<th>NBJK (n = 860)</th>
<th>SAMUHA (n = 180)</th>
<th>SACRED (n = 500)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. strains in your relationships with friends and family because of your caring responsibilities?</td>
<td>A lot</td>
<td>369</td>
<td>335</td>
<td>09</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>Quite a bit</td>
<td>613</td>
<td>395</td>
<td>74</td>
<td>144</td>
</tr>
<tr>
<td></td>
<td>Little</td>
<td>371</td>
<td>77</td>
<td>97</td>
<td>197</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>187</td>
<td>53</td>
<td>0</td>
<td>134</td>
</tr>
<tr>
<td>B. “drifting apart” from friends and family because your caring responsibilities limit the time you have to keep in contact with them?</td>
<td>A lot</td>
<td>186</td>
<td>146</td>
<td>09</td>
<td>31</td>
</tr>
<tr>
<td></td>
<td>Quite a bit</td>
<td>699</td>
<td>493</td>
<td>73</td>
<td>133</td>
</tr>
<tr>
<td></td>
<td>Little</td>
<td>491</td>
<td>172</td>
<td>98</td>
<td>221</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>164</td>
<td>49</td>
<td>0</td>
<td>115</td>
</tr>
<tr>
<td>C. feeling isolated and lonely because of the situation you are in?</td>
<td>A lot</td>
<td>207</td>
<td>160</td>
<td>12</td>
<td>35</td>
</tr>
<tr>
<td></td>
<td>Quite a bit</td>
<td>461</td>
<td>254</td>
<td>93</td>
<td>114</td>
</tr>
<tr>
<td></td>
<td>Little</td>
<td>574</td>
<td>280</td>
<td>75</td>
<td>219</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>298</td>
<td>166</td>
<td>0</td>
<td>132</td>
</tr>
<tr>
<td>D. not getting the support you need from family and friends?</td>
<td>A lot</td>
<td>119</td>
<td>24</td>
<td>06</td>
<td>89</td>
</tr>
<tr>
<td></td>
<td>Quite a bit</td>
<td>371</td>
<td>160</td>
<td>79</td>
<td>132</td>
</tr>
<tr>
<td></td>
<td>Little</td>
<td>502</td>
<td>208</td>
<td>95</td>
<td>199</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>548</td>
<td>468</td>
<td>0</td>
<td>80</td>
</tr>
</tbody>
</table>
Carers report a number of concerns about how caring impacts on their ability to maintain relationships with friends and family. In particular, significant numbers of carers express serious concern about the strain their caregiving activities place on their relationships with friends and family members (63.9% reporting ‘a lot’ or ‘quite a bit’ of concern) as well as concern that they are drifting apart from friends as a result of the limited time they have to keep in contact with them (57.5% reporting ‘a lot’ or ‘quite a bit’ of concern). Feeling isolated or unsupported by friends or family is a cause for concern for fewer carers (43.4% and 31.8% respectively reporting ‘a lot’ or ‘quite a bit’ of concern), though they still provoke significant concern amongst a number of carers. Carers from NBJK experience much more anxiety than carers from SAMUHA and SACRED, with regard to the stress that their caring activities puts on their relationships with friends and relatives and to their anxieties about losing contact with friends. In comparison, SACRED carers report much lower levels of anxiety across the board about the impact that caring has on their relationships.
Concerns about finances

<table>
<thead>
<tr>
<th>Questions</th>
<th>Variable</th>
<th>TOTAL (n = 1540)</th>
<th>NBJK (n = 860)</th>
<th>SAMUHA (n = 180)</th>
<th>SACRED (n = 500)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. - your financial situation?</td>
<td>A lot</td>
<td>246</td>
<td>191</td>
<td>21</td>
<td>34</td>
</tr>
<tr>
<td></td>
<td>Quite a bit</td>
<td>728</td>
<td>493</td>
<td>96</td>
<td>139</td>
</tr>
<tr>
<td></td>
<td>Little</td>
<td>436</td>
<td>113</td>
<td>62</td>
<td>261</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>130</td>
<td>63</td>
<td>01</td>
<td>66</td>
</tr>
<tr>
<td>B. - having to cover extra costs of caring (eg. trips to hospital, medication)?</td>
<td>A lot</td>
<td>134</td>
<td>113</td>
<td>17</td>
<td>06</td>
</tr>
<tr>
<td></td>
<td>Quite a bit</td>
<td>520</td>
<td>296</td>
<td>85</td>
<td>137</td>
</tr>
<tr>
<td></td>
<td>Little</td>
<td>547</td>
<td>312</td>
<td>76</td>
<td>159</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>339</td>
<td>139</td>
<td>02</td>
<td>198</td>
</tr>
</tbody>
</table>

Finances are a serious concern (‘a lot’ or ‘quite a bit’) for 63.2% of carers. In NBJK project areas, the number of carers expressing serious concern about their financial situation is a high as 79.5%, though this is lower in other areas (65.0% for SAMUHA and only 34.6% for SACRED). Specific concerns about covering the extra costs associated with caring cause significant anxiety to fewer carers (42.5%) than more general financial concerns, suggesting that other factors also contribute to carers’ financial worries. More research will be needed to break this down further and explore what other factors contribute to carers’ financial concerns.
Concerns about physical health

<table>
<thead>
<tr>
<th>Questions</th>
<th>Variable</th>
<th>TOTAL (n = 1540)</th>
<th>NBJK (n = 860)</th>
<th>SAMUHA (n = 180)</th>
<th>SACRED (n = 500)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. - your own physical health?</td>
<td>A lot</td>
<td>174</td>
<td>94</td>
<td>04</td>
<td>76</td>
</tr>
<tr>
<td></td>
<td>Quite a bit</td>
<td>680</td>
<td>488</td>
<td>78</td>
<td>114</td>
</tr>
<tr>
<td></td>
<td>Little</td>
<td>429</td>
<td>131</td>
<td>95</td>
<td>203</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>257</td>
<td>147</td>
<td>03</td>
<td>107</td>
</tr>
<tr>
<td>B. - your caring role making your physical health worse?</td>
<td>A lot</td>
<td>66</td>
<td>47</td>
<td>05</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Quite a bit</td>
<td>524</td>
<td>390</td>
<td>74</td>
<td>60</td>
</tr>
<tr>
<td></td>
<td>Little</td>
<td>414</td>
<td>175</td>
<td>98</td>
<td>141</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>536</td>
<td>247</td>
<td>03</td>
<td>288</td>
</tr>
</tbody>
</table>

55.5% of carers express significant concern (‘a lot’ or ‘quite a bit’) about their own physical health. Fewer carers are explicitly concerned about their physical health deteriorating as a direct result of their caring activities, though that still leaves a significant number of carers (38.3%) who feel that their caring duties directly adversely impact their physical health. Unlike NBJK and SACRED carers, in SAMUHA’s project area carers report almost equal levels of generalised concern about their physical health (45.6%) and specific concern about the impact that caring has on their physical health (43.9%), suggesting that more SAMUHA carers see a relationship between the two. Again, SACRED carers express lower levels of concern than NBJK and SAMUHA.
## Concerns about mental health

<table>
<thead>
<tr>
<th>Questions</th>
<th>Variable</th>
<th>TOTAL (n = 1540)</th>
<th>NBJK (n = 860)</th>
<th>SAMUHA (n = 180)</th>
<th>SACRED (n = 500)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. being unable to cope with the ‘constant anxiety’ of caring?</td>
<td>A lot</td>
<td>295</td>
<td>272</td>
<td>06</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>Quite a bit</td>
<td>650</td>
<td>447</td>
<td>81</td>
<td>122</td>
</tr>
<tr>
<td></td>
<td>Little</td>
<td>382</td>
<td>80</td>
<td>92</td>
<td>210</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>213</td>
<td>61</td>
<td>01</td>
<td>151</td>
</tr>
<tr>
<td>B. feeling depressed?</td>
<td>A lot</td>
<td>257</td>
<td>215</td>
<td>18</td>
<td>24</td>
</tr>
<tr>
<td></td>
<td>Quite a bit</td>
<td>668</td>
<td>464</td>
<td>107</td>
<td>97</td>
</tr>
<tr>
<td></td>
<td>Little</td>
<td>402</td>
<td>111</td>
<td>55</td>
<td>236</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>213</td>
<td>70</td>
<td>0</td>
<td>143</td>
</tr>
<tr>
<td>C. being unable to see anything positive in your life?</td>
<td>A lot</td>
<td>202</td>
<td>176</td>
<td>09</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>Quite a bit</td>
<td>488</td>
<td>358</td>
<td>73</td>
<td>57</td>
</tr>
<tr>
<td></td>
<td>Little</td>
<td>613</td>
<td>226</td>
<td>97</td>
<td>190</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>237</td>
<td>100</td>
<td>01</td>
<td>136</td>
</tr>
<tr>
<td>D. lack of sleep because of worry or stress?</td>
<td>A lot</td>
<td>141</td>
<td>113</td>
<td>09</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>Quite a bit</td>
<td>462</td>
<td>296</td>
<td>77</td>
<td>89</td>
</tr>
<tr>
<td></td>
<td>Little</td>
<td>631</td>
<td>312</td>
<td>92</td>
<td>227</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>306</td>
<td>139</td>
<td>02</td>
<td>165</td>
</tr>
<tr>
<td>E. feeling so exhausted you can’t function properly?</td>
<td>A lot</td>
<td>89</td>
<td>60</td>
<td>07</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>Quite a bit</td>
<td>369</td>
<td>170</td>
<td>95</td>
<td>104</td>
</tr>
<tr>
<td></td>
<td>Little</td>
<td>450</td>
<td>161</td>
<td>76</td>
<td>213</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>632</td>
<td>467</td>
<td>02</td>
<td>163</td>
</tr>
</tbody>
</table>
Of the different mental health indicators measured, feelings of anxiety and depression are of greatest concern to carers, with 61.4% and 60.1% of carers respectively reporting significant (‘a lot’ or ‘quite a bit’) concern about those feelings and another 44.8% reporting being unable to see any positives in their lives. Other mental health impacts such as a lack of sleep (39.2% reporting ‘a lot’ or ‘quite a bit’ of concern) and exhaustion (29.7% reporting ‘a lot’ or ‘quite a bit’ of concern) are of less concern to carers. This same hierarchy of concerns is recorded by NBJK carers, whereas SAMUHA and SACRED carers report fairly consistent levels of significant (‘a lot’ or ‘quite a bit’) concern for each mental health indicator (with the exception of depression which outranks other health indicators for SAMUHA carers).
Concerns about being treated differently

<table>
<thead>
<tr>
<th>Questions</th>
<th>Variable</th>
<th>TOTAL (n = 1540)</th>
<th>NBJK (n = 860)</th>
<th>SAMUHA (n = 180)</th>
<th>SACRED (n = 500)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How concerned are you about: people treating you differently because of the illness or condition of the person you care for?</td>
<td>A lot</td>
<td>63</td>
<td>25</td>
<td>02</td>
<td>36</td>
</tr>
<tr>
<td></td>
<td>Quite a bit</td>
<td>532</td>
<td>395</td>
<td>54</td>
<td>83</td>
</tr>
<tr>
<td></td>
<td>Little</td>
<td>498</td>
<td>159</td>
<td>123</td>
<td>216</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>447</td>
<td>281</td>
<td>01</td>
<td>165</td>
</tr>
</tbody>
</table>

Compared to other concerns rated by carers, being treated differently by others is less of a concern, though it still represent a significant (‘a lot’ or ‘quite a bit’) concern for 38.6% of carers. Anxieties about being treated differently are more acute for NBJK carers (48.8%) than for carers from SAMUHA (21%) and SACRED (23.8%) project areas.
### Desire for further support

<table>
<thead>
<tr>
<th>Questions</th>
<th>Variable</th>
<th>TOTAL (n = 1540)</th>
<th>NBJK (n = 860)</th>
<th>SAMUHA (n = 180)</th>
<th>SACRED (n = 500)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would you like: more support to help you in your role as a carer?</td>
<td>No not at all</td>
<td>70</td>
<td>40</td>
<td>03</td>
<td>27</td>
</tr>
<tr>
<td></td>
<td>Yes, a little</td>
<td>1004</td>
<td>660</td>
<td>147</td>
<td>197</td>
</tr>
<tr>
<td></td>
<td>Yes, a lot</td>
<td>466</td>
<td>160</td>
<td>30</td>
<td>276</td>
</tr>
</tbody>
</table>

Unsurprisingly, the vast majority of carers (95.5%) indicate that they would welcome more support in their caring activities. Although carers express significant interest in receiving additional support in all project areas, SACRED carers record the greatest demand for additional support, with 39.4% of carers requesting ‘a lot’ of extra support’, compared to just 16.6% of SAMUHA carers and 18.6% of NBJK carers.
References


# Appendix – Baseline Data Collection Instrument

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Individual Code and Year</td>
<td>(eg. 0001 / 2014)</td>
</tr>
<tr>
<td>2</td>
<td>Name of Carer</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Gender</td>
<td>Male ☐ Female ☐</td>
</tr>
<tr>
<td>4</td>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Type of family</td>
<td>Joint ☐ Nuclear ☐</td>
</tr>
<tr>
<td>7</td>
<td>Total number of people living in the house</td>
<td>Please give details including adult/child, male/female</td>
</tr>
<tr>
<td>8</td>
<td>Do they have an identity card?</td>
<td>Yes ☐ No ☐</td>
</tr>
<tr>
<td>9</td>
<td>Main person they are caring for</td>
<td>Name</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Age</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Gender</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Condition</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Since when?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other</td>
</tr>
<tr>
<td>10</td>
<td>Are they caring for any other family members?</td>
<td>If yes, please give details:</td>
</tr>
<tr>
<td></td>
<td>Eg. another person who is elderly, chronically ill, disabled, etc.</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Postal address inc. village name</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Phone number</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>District and State</td>
<td></td>
</tr>
<tr>
<td>----</td>
<td>-------------------</td>
<td></td>
</tr>
<tr>
<td>13.1</td>
<td>Is the carer currently having any health problem or disability? Eg. physical problems like back pain or mental health issues like depression or anxiety, etc.</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>13.2</td>
<td>If yes, please explain what the problems/disabilities are</td>
<td>Problems/disabilities:</td>
</tr>
<tr>
<td>13.3</td>
<td>If yes, are they receiving any treatment/support?</td>
<td>What treatment and where?</td>
</tr>
<tr>
<td>13.4</td>
<td>If they are not receiving treatment for a problem, why not?</td>
<td>Not willing to get treatment [ ] Did not know about the treatment places [ ] Treatment places are far away from village [ ] There was no other carer to look after their relative [ ]</td>
</tr>
<tr>
<td>14.1</td>
<td>Education level of carer(Studied up to) (see notes below)</td>
<td></td>
</tr>
<tr>
<td>14.2</td>
<td>Present education status of carer (see notes below)</td>
<td>Studying [ ] Vocational Training [ ]</td>
</tr>
<tr>
<td>15.1</td>
<td>Is the carer earning?</td>
<td>Yes [ ] No [ ] Not applicable [ ]</td>
</tr>
<tr>
<td>15.2</td>
<td>If yes, type of work and amount earned per month?</td>
<td>Type of work</td>
</tr>
<tr>
<td>15.3</td>
<td>If the carer is not earning, why not?</td>
<td>No work available [ ] No one else to look after the cared for relative [ ] Unable to work because of the carer’s own poor health [ ] Other [ ]</td>
</tr>
<tr>
<td>Question</td>
<td>Details</td>
<td>Answer Options</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>---------</td>
<td>-------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>15.4 Is there a particular skill or experience that could help the</td>
<td></td>
<td></td>
</tr>
<tr>
<td>carer to take up a livelihood activity? Or is there any training they</td>
<td></td>
<td></td>
</tr>
<tr>
<td>are interested to undertake?</td>
<td>Details</td>
<td></td>
</tr>
<tr>
<td>16 Any other income to the household?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disability pension</td>
<td>Old age pension</td>
<td></td>
</tr>
<tr>
<td>Retirement pension</td>
<td>Widow pension</td>
<td></td>
</tr>
<tr>
<td>Income through property</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td>mention</td>
<td>Nothing</td>
</tr>
<tr>
<td>17.1 Is the carer a member of any community Self Help Group (SHG)?</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>17.2 Is the carer a member of any other community groups?</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Mention.........................</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18.1 Was the carer or the person they are looking after given a loan/</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>grant?</td>
<td>Amount</td>
<td>Not applicable</td>
</tr>
<tr>
<td>18.2 If yes, what is the amount?</td>
<td>Amount</td>
<td>Not applicable</td>
</tr>
<tr>
<td>18.3 Source of loan</td>
<td>Carers Project</td>
<td>Bank</td>
</tr>
<tr>
<td>Government scheme</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td>mention</td>
<td>Not applicable</td>
</tr>
<tr>
<td>19.1 Is the person they are looking after earning?</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>19.2 If yes, what is the type of work and amount earned per month?</td>
<td></td>
<td>Type of work</td>
</tr>
<tr>
<td>19.3 Is the person they are looking after a member of SHG?</td>
<td></td>
<td>Yes</td>
</tr>
</tbody>
</table>
## MEASURE OF WELLBEING:

### Questionnaire:

<table>
<thead>
<tr>
<th>Question</th>
<th>Concern Level</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>20.1</strong> How concerned are you about:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- not having enough time to yourself?</td>
<td>A lot</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- not being able to take a break from caring?</td>
<td>Quite a bit</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- not being able to plan for the future?</td>
<td>A little</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- not being able to continue caring (eg. because you are ill yourself)?</td>
<td>Not at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>20.2</strong> How concerned are you about:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- strains in your relationships with friends and family because of your caring responsibilities?</td>
<td>A lot</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- “drifting apart” from friends and family because your caring responsibilities limit the time you have to keep in contact with them?</td>
<td>Quite a bit</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- feeling isolated and lonely because of the situation you are in?</td>
<td>A little</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- not getting the support you need from family and friends?</td>
<td>Not at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>20.3</strong> How concerned are you about:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- your financial situation?</td>
<td>A lot</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- having to cover extra costs of caring (eg. trips to hospital, medication)?</td>
<td>Quite a bit</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>20.4</strong> How concerned are you about:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- your own physical health?</td>
<td>A lot</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- your caring role making your physical health worse?</td>
<td>Quite a bit</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>20.5</strong> How concerned are you about:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- being unable to cope with the “constant anxiety” of caring?</td>
<td>A lot</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- feeling depressed?</td>
<td>Quite a bit</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>- being unable to see anything positive in your life?</td>
<td>A little</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>- lack of sleep because of</td>
<td>Not at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Responses</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>-------------------------------------------------------------------------</td>
<td>--------------------</td>
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</tr>
<tr>
<td>20.6 How concerned are you about people treating you differently because of the illness or condition of the person you care for?</td>
<td>A lot, Quite a bit, A little, Not at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20.7 Would you like more support to help you in your role as a carer? (please tick ONE box)</td>
<td>No, not at all, Yes, a little, Yes, a lot</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21.1 Ask the carer to list 3 issues/needs that present them with the most difficulty in relation to their caring role and how it affects their life and the life of their family.</td>
<td>1, 2, 3</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>21.2 Does the carer have any ideas how to relieve the issues/needs they have identified in question 20.1?</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
22 Data collection date    DD  MM  YYYY

23 Data collection location
   (ie camp, home, clinic, SHGs, etc)

24 Data collected by    Name    Position    Signature

**Note:** use the guidelines for answering the following questions;

- 14.1 – for children give the present class; for adults give the highest education received; if the child has never been to school, mention 'nil'.
- 14.2 – answer only for children; for adults tick 'Not applicable'
“This is the first time an effort has been made to build evidence about the day to day lives of caregivers and the impact of caregiving on their lives....All other organisations need to learn from their research experience and reflect for including the same in their programmes.”

Dr N. Janardhana