

Report on Consultation on the Needs of Carers in India and South Africa

November 2011 to March 2012

Anil Patil



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Sian Edwards has been untiring in her support, answering all manner of enquiries and advising me all along the way. Chris Underhill has been, and continues to be, my guide and critical friend. I look forward to continuing the Carers Worldwide journey with both of them.

There are so many organisations and individuals in India and South Africa who generously gave up their time to meet me and add their insights and knowledge to the consultation process – huge thanks to them for facilitating so many contacts.

Last, but by no means least, I extend my heartfelt thanks to all the carers who shared a part of their lives with me. Their stories and aspirations will continue to inspire me as Carers Worldwide enters its next phase.

PREFACE

When our own beautiful daughter was born with Down Syndrome, my wife and I found ourselves launched into the world of being carers. This was a privilege but also a challenge and we depended on support from a variety of external sources – state, community, professionals, friends and family. It is daunting to imagine ourselves in the same situation but without all these supports. But this is the situation faced by many carers in developing countries.

Working with disability and mental health NGOs in India over six years, I came across numerous carers. Through their effort, patience, knowledge, understanding, companionship, determination and compassion, these carers transformed the lives of the people for whom they were caring. Certain experiences from this time still stick in my mind. Carers would ask, ‘What happens when I die?’ We never came close to answering this troubling and yet most basic concern. Do we as development workers need to provide an answer for this or is it our role to facilitate the process where carers themselves find the answer. Looking back, I realise that community development workers (and that includes me as well) are often all too quick to label carers as non-cooperative if they do not follow our advice or participate fully in the process of caring for their relative. But is it carers who are the problem or is it our inability to understand the various issues that are affecting a carer’s involvement? During one consultation, a young carer expressed that carers are very happy to support and provide all the necessary intervention for the person requiring support, but asked, ‘What about the needs of carers? Who is going to listen to us or look after us?’

Whilst studying for my MSc in community disability studies, I completed a dissertation on ‘*The Burden of Mental Illness on the Family in Less Developed Countries*’. My review of the available literature on this topic demonstrated that a significant burden is reported. Types of burden include social and family related, occupational, financial and physical, with financial being the most consistent in occurrence across different cultures.

These three experiences have had a profound impact on me and my plans for the future. I have an aspiration to start a new initiative taking up the issue of carers, particularly in a developing country context. The primary focus will be to facilitate existing disability, mental health, HIV/AIDS and other social NGOs to include carers and their needs within their programmes. These are challenging times, but I think the time is right for me to embark upon this new initiative and take up the challenge to work on carers’ issues.

My journey towards establishing this initiative has been assisted by a grant from the Andrews Charitable Trust, given for the specific purpose of carrying out a consultation with carers and organisations involved in working with the disabled, mentally ill, people living with HIV/AIDS, the chronically ill and the elderly. I conducted two consultation visits, first to India and then to South Africa. This report is the culmination of the consultation process.



Maya with children at the Association of People with Disability, Bangalore, India

EXECUTIVE SUMMARY

The contribution of carers to society is undervalued and underestimated. In developing countries, there is virtually no recognition of the effort and commitment made by the millions of people caring for the disabled, sick, dying or elderly. Consideration of the needs of carers – physical, emotional, economic or social – is virtually non-existent. There is no organisation working solely to address the issues facing carers.

In undertaking the consultation, my aim was to further establish the need for such an organisation and to formulate an approach to working with local organisations, NGOs, international NGOs and governments to sensitise them to the needs of carers and to support them to meet those needs. The number of people involved in caring is on the increase and there is an urgent need to address the issues facing them if they are to continue making the enormous contribution to society that they currently do. Without this, countries are in imminent danger of facing the collapse of the social and caring framework on which they currently rely. Carers want to care and are keen to work together with local organisations to support themselves, their families and their communities. They are able to clearly articulate their hopes and plans, and are looking to organisations and governments to implement simple measures to improve the quality of their lives and those for whom they care.

This report outlines the consultation process and my key findings around the needs and aspirations of carers. It proposes a model, key to the development of which is the Carers Worldwide Forum, an innovative approach to bringing key stakeholders together to develop and implement ongoing strategy. Three approaches have been developed – advocacy, social enterprise and day care, which in combination will address the varied needs of carers in different situations and settings.

- Advocacy will enable carers' views and wishes to be heard. Groups of carers will come together to provide emotional support and a platform from which they can advocate at local and state level for change. This approach will also look at providing economic stability for the many carers who are unable to engage in regular employment due to their caring responsibilities. Livelihood opportunities will be explored at an individual or group level, and links will be made with existing activities.
- Social enterprise will involve setting up local companies which will provide personal care assistants for families able to pay for such a service. In turn this will provide employment and also generate funds required to run other aspects of Carers Worldwide's programmes.
- Day care centres will be established in slums or townships by local communities. They will provide a place where carers can leave the person for whom they care, knowing that their needs are being met, while they go to work. The centres will be staffed by existing caregivers or members of the local community.

I have set out initial plans for piloting these approaches, initially in India and later in South Africa.

I propose to establish a new initiative, Carers Worldwide. I have outlined strategic objectives and a business plan outlining the way in which I will go about setting up an effective, well-governed organisation. Key to its sustainability will be a targeted fundraising strategy and a style of leadership aimed at developing local skills and capabilities.

There is a great desire for change amongst the individuals and organisations that I met during the consultation process. The initial consultation findings are shocking in terms of the extent of need and the individual experiences and situations discovered. Organisations are doing incredible work in their respective fields but admit that nothing is being done to address the needs of carers. There is universal agreement amongst the various stakeholders that it will be possible to achieve significant change through the implementation of a targeted and sustained approach.

I believe that Carers Worldwide can achieve sustained positive change for carers in developing countries by addressing the issues of recognition, social and economic concerns. For the sake of the carers that I met in India and South Africa, and for the countless others who devote their lives to caring, this change must take place, sooner rather than later.

BACKGROUND

The life of a carer

The life of a carer is one of challenge and change. Caring can be a rewarding experience, but it undoubtedly has a significant impact on the carer's life. They often find themselves having to adapt to the needs of the person they are caring for, leaving little time for them to take care of their own needs. Carers consequently often experience ill health and many suffer from poverty and even discrimination. Carers give so much to society, but their contribution goes largely unrecognised. These issues are prevalent in developing countries, where there is little or no state support or provision for families affected by disability, mental illness, HIV/AIDS, chronic illness or old age.



Lalappa from Andhra Pradesh, India

Carers¹ devote large parts of their own lives to improving the lives of others – this is not as part of their job, but is undertaken voluntarily and often in addition to working. For the sick, the frail, the vulnerable and the elderly, carers provide invaluable help and support in ways which might otherwise not be available. Whilst it can be hugely rewarding, caring can also be intensely frustrating and often problematic. It can be costly in terms of life chances, financial security and health. People who care do so because they want to help the people they care about, but it often means that they end up in a juggling act, trying to balance the support they give with the other responsibilities they have in their lives. For many carers, the tasks of looking after their own health, combining caring with work and even making time to take a break can be a major challenge.

If carers are to have the same opportunities as everyone else in society and to be able to have a life outside caring, there is a need to improve carers' support and increase both the understanding and recognition of the amazing things that carers do and achieve. This means ensuring that support for carers' health and wellbeing is improved as well as ensuring that carers are able to access education and livelihood opportunities. The needs of all carers should be both understood and met to enable each carer to develop and thrive as individuals, thereby improving their lives and the lives of those they care for.

The scale of the issue

Although research on the numbers of carers in developing countries has undoubtedly been carried out on small scales, there is no easily accessible data comparable to that provided from Western countries.

It is estimated that in the UK, 1 in 8 adults (around six million people) are carers. Taking this figure as a guide, if we take a country the size of India with a population of 1.2 billion, this equates to a figure of 150 million carers (this figure also includes child carers). Until specific detailed research is carried out, this figure cannot be verified. However, it is my opinion that once we have conducted initial research, we will find that the actual figures are far higher.

Long-term care for people with chronic illnesses and disabilities presents an urgent challenge around the world. A recent WHO study estimates that in many developing countries the need will increase by as much as 400% in the coming decades.

¹ "Carer" means an individual of any age who cares for or nurses a relative, friend or partner requiring this help due to physical or mental ill health, disability, old age, frailty, substance misuse or any other cause.

In addition to the scale of the issue in terms of numbers, it should also be noted that however challenging the life of a carer, there is at least some recognition within the West of the work carried out and the colossal contribution made by carers. In contrast, there is virtually no awareness, let alone recognition or support for carers within developing countries, either at government or community level.

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

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

"We are voiceless, the most marginalised and excluded in socio-cultural activities"
Ruby Singh, mother to a child with autism, Bangalore

Over-burdened, under-supported carers face harsh realities in their everyday lives with existing poverty and gender being additional exacerbating factors. A lack of support services impacts directly on carer's health and prevent carers having a life outside of caring.

TERMS OF REFERENCE AND OBJECTIVES

I developed a set of objectives for the consultation process and these were circulated to the organisations and individuals to be visited, along with the terms of reference, as outlined below.

Purpose of visit:

- To explore and consult on the needs of carers in developing countries and how these might be addressed as part of the development agenda.
- To seek the opinions of experts within the sectors working with disability, mental health, HIV/AIDS, chronic illness and the elderly in both urban and rural communities.
- To establish contacts with potential funders to identify opportunities for developing future responses.

Expected Outcomes:

Four objectives were identified when the Andrews Charitable Trust agreed to fund the exploratory visits.

1. A better understanding of the needs and possible ways of addressing them, through consultations held with potential partners, carers and resource organisations in India and South Africa.
2. Verification of an approach to address these needs, through consultation with experts and organisations already working within the sectors of disability, mental health, HIV/AIDS, chronic illness and old age.
3. A consultation report which at the end articulates clearly an approach to address the main problems identified during the research.
4. Initial contacts established with potential funders in the UK so that fundraising possibilities and prospects of success are identified.

Where I visited:

I visited India from 9th November to 4th December 2011. During that time I travelled extensively across the country and met with 22 organisations and individuals. See Appendix 1 for details.

I visited South Africa from 10th February to 2nd March. There, I again travelled across the country, meeting a total of 24 organisations and individuals. See Appendix 1 for details.

Outcome 1 – Understanding the needs of carers

Much has been written in the West about the specific needs and experiences of carers. It was important to verify if these were the same in India and South Africa. I consulted with carers, potential partners and resource organisations working in the fields of disability, mental health, HIV/AIDS, chronic illness and old age, covering both rural and urban settings in an effort to gain a broad and balanced picture.

Through the exercises carried out at the carers' meetings, the following **common needs** emerged:

- Opportunity for a break and practical support
- Information
- Training in caring skills
- Emotional support
- Improved communication and problem solving
- Stress management
- Involvement in planning and delivery of services



Carers also talked about the impact of caring, resulting in:

- Stress
- Overburden and burn-out
- Stressful relationship
- Health problems
- Limitations on employment
- Limitations on finances
- Limitations on relationships and social contacts
- Limitations on education
- An end to childhood (for child carers)

“Carers don’t have a choice but to lead life and there is no one to talk to”
Nomusa Njoko, who is HIV+ and works as Deputy Manager of Social Marketing & Mobilisation, Government of KZN province

There was an overwhelming feeling about the extent to which caring creates a range of emotions, which are sometimes conflicting:

- Feeling trapped
- Feeling of grief and loss
- Feeling guilty
- Feeling angry
- Feeling of satisfaction in supporting a loved one
- Feeling of frustration that no-one appreciates them

The majority of carers are women – mothers, wives, daughters. Naturally, men also become carers, and there is little difference between the needs of female and male carers.

Many carers are already in contact with community based organisations and NGOs. This contact is usually as a consequence of the person they are caring for. For example, the mother of a child with cerebral palsy in South India attends a clinic run by Samuha Samarthya and learns how to carry out physiotherapy to teach her child to walk. The wife of a man infected with the HIV virus admits him to the local hospice for palliative care as his condition worsens.

However, at no time are the needs of the carer addressed. **A significant number of the organisations visited stated that they were working with carers. In actual fact, they were working with carers in order to meet the needs of the person being cared for, and not taking account of the carer as an individual.**



Mothers of disabled children discussing the issues facing them in their day to day lives, Andhra Pradesh, India

There is little structured emotional support or help dealing with the impact of the condition on the wider family and how they are viewed by society. There is little or no opportunity for respite and the carer frequently feels they are the only person carrying the load. The wider economic needs of the carer and family are not a focus, and many of these families live in extreme poverty.

Most of the professionals, NGO managers and Government officials that I met acknowledged that there is a serious issue around the lack of recognition of carers – both the amount that they contribute and their needs.

“In my opinion caregivers are an invisible community, sometimes even invisible to themselves. I think it is important to address this invisibility, which is the first thing that has to change.” Dr Ajay Kumar, Psychiatrist working in Hospet, India

During a meeting of NGO heads involving 22 Bangalore based organisations, I sought opinions on the issue of carers and their needs. The Commissioner of Disability for the Government of Karnataka was also in attendance. All those present highlighted that minimal support is provided to carers. They realised that the focus has always been on the person who has been affected and how carers can be involved to meet their needs, rather than any attention being given to the primary carers and the issues that are affecting their own lives.

A clear picture of **priorities** has emerged, including:

- Raising awareness of the needs of carers amongst the community, organisations and government
- Recognition of family carers as partners in caring
- Support groups for family carers and community carers
- Debriefing opportunities, a self screening system to identify potential 'burnout' and personal counselling for community based carers
- Respite care for family carers
- Developing livelihood opportunities to support family income
- Developing a clear picture of caregiving through research



Khonzaphi Zondi, a grandmother at the Ethembeni project who looks after her daughter's children who are HIV positive



Srinivas and his 13 year old daughter, Gowri, who has cared for him since he sustained a spinal cord injury after an accident

The consultation process has been key in confirming that there is a requirement for an organisation to promote the needs of carers in developing countries. It has also shown that there is a will for this amongst carers, staff, development professionals and even Government.

There is no organisation in either India or South Africa working specifically on the issue of carers and their needs.

As a result of the consultation, a clearer picture of the ways in which this organisation should work has emerged – see Outcome 2 for details.

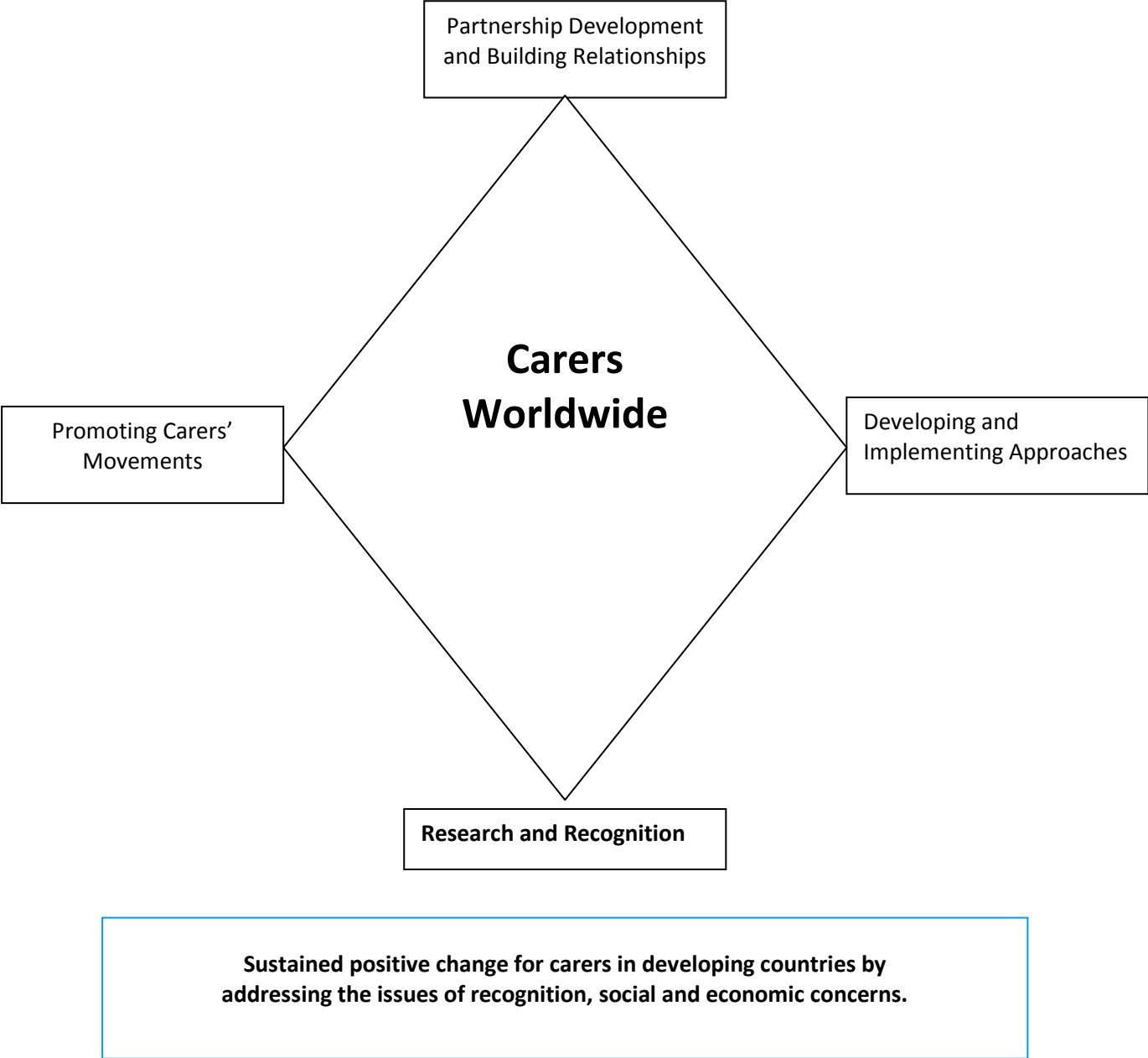


Meeting with staff and carers at Samuha Samarthya, northern Karnataka, India

Outcome 2 – Verification of an approach to address carers’ needs

Before my visits to India and South Africa, I had a conceptual framework of how Carers Worldwide should approach working with carers. This has since evolved and I have now developed the framework further, based on the evidence. It has also become clearer that different strands will have greater or lesser prominence depending on the existing situation within a particular country.

CARERS WORLDWIDE MODEL



a) Partnership development and building relationships

Through developing working partnerships with existing well-established NGOs, we can build understanding around the needs of carers and initiate specific programmes to improve the lives of carers (see models for more information on details). Through this process, both carers and organisations will be empowered.

Partnerships will also be developed with government agencies, academics and policy makers.

b) Developing and implementing approaches

See later information on 'approaches'.

The approaches will be implemented based on the existing knowledge base and programmes of each individual organisation. For example, an organisation already successfully engaged in developing livelihoods options would need support to develop work specifically with carers, not on how to develop livelihoods.

c) Research and recognition

Little research has been done into the levels and impact of caring in the developing world. Carers Worldwide can add quantitative and qualitative information and drive forward an agenda of research, leading to greater recognition of the contribution of carers and in turn generating knowledge and contributing to policy change.

Many people in developing countries are unaware of the value, both societal and economic, that carers contribute to their society and do not realise that they themselves may already be or someday become carers. Carers often do not themselves recognise that they are doing something extraordinary. Carers play a crucial role in enhancing access to support and increasing the quality and sustainability of care for their family and friends. However, society and even the family do not recognise this contribution and so nothing is done to support carers.

Enhanced awareness and respect will provide support for carers by enabling them to:

- make informed decisions about their level of involvement in caregiving.
- recognise themselves as carers and become aware of their rights and responsibilities.

In turn, an increased awareness of the value and importance of carers amongst the wider population will result in changes of attitude, helping to lead to:

- a decrease in the carer's feeling of isolation
- an increase in emotional and practical support for the carer
- a reduction in the stigma attached to illness and the caring role
- an improvement in the services available to carers.

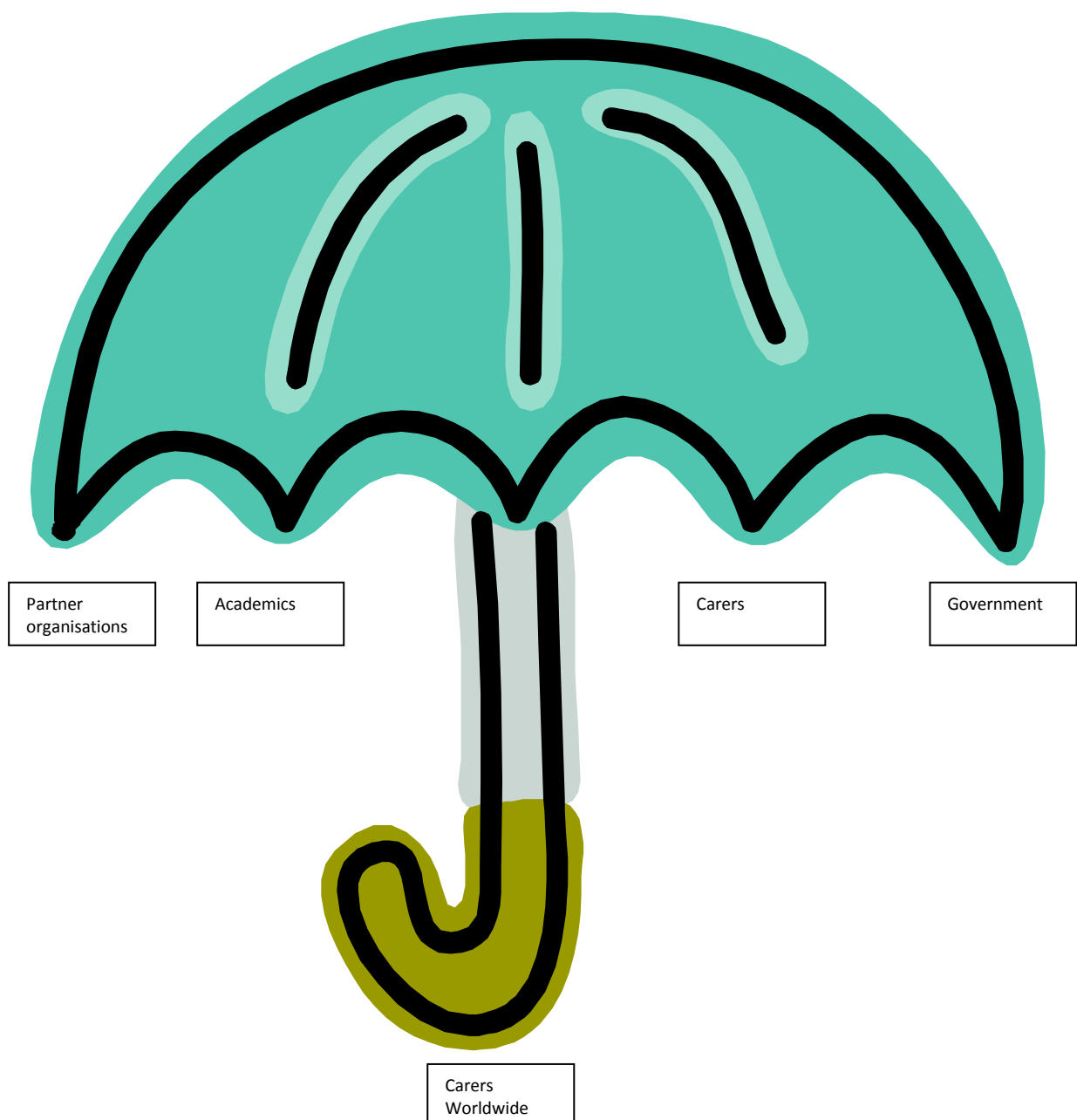
d) Promoting carers' movements

Creating a platform for carers to come together will enable them to share experiences, gain mutual support, initiate group livelihood activities and potentially in time influence and shape activity at local, regional and national level. Self help groups could be facilitated at local level, which would then be federated upwards. It is envisaged that these would gain a power similar to those of disabled people's organisations or women's organisations, which are now established features in the civil society of many developing countries.

Carers Worldwide Forum

Key to the development of this model is the Carers Worldwide Forum:

- a group of partners working together to develop and implement strategy for addressing the needs of carers
- will act as a 'think tank' in terms of sharing experience, generating knowledge and driving the initiative forward
- from NI, there would be a programme co-ordinator and an administrator
- partner organisations would represent a range of issues – disability, HIV/AIDS, mental health, elderly
- each organisation on the forum will be responsible for implementation in their particular field
- the organisation head/senior manager responsible for implementing activities will be the representative
- potential to act as an advisory body to the Government
- the Forum will meet 4 times a year



Carers Worldwide Approaches

Three potential approaches are emerging.

Running through each of them will be themes of **empowering carers** and bringing about **recognition of the valuable contributions** carers make to the person they are caring for as well as to the society.

1. Advocacy Approach

The Advocacy approach is about enabling carers' views and wishes to be heard. This approach will be mainly focussed in rural areas.

In this approach, carers, including children and young carers, who share similar experiences are brought together to learn and support each other. They will access better information and advice about the health or condition of the person they are caring for, how to cope with it and about the services and benefits available to them.

In time, they will develop the skills to advocate for themselves and/or on behalf of their peer group. They will have the support of their peers to express themselves, develop their own ideas and find solutions to problems. In other words, they will be learning to represent the views of all carers, with the intention of influencing for change. It is envisaged that this could develop into a 'Carers Movement' which would have the potential to gain a power similar to those of disabled people's organisations or women's organisations, which are now established features in the civil society of many developing countries.

An additional component of the advocacy approach will involve livelihoods – exploring opportunities for income generation to augment family resources. Economic instability is a key feature of households where one or more members are cared for and another is a carer. In addition, carers may feel that their world revolves around caring, without much room in it for them. Many carers find that having an activity outside of their caring role is important to them, giving them a sense of identity and boosting their confidence. Local livelihood opportunities will be explored, either for an individual or as a group. There may be chances to access Government schemes. For example, in India, representation will be made to the National Rural Employment Guarantee Act, with the aim of recognising the unique situation of carers, specifically their limited opportunities to take up employment. If we are successful in this, there would be a massive impact across the country as this is a central Government scheme.

2. Social Enterprise approach

This will initially be piloted in the urban areas.

Many families are not able to meet the needs of their family members, be they elderly, sick, disabled. Many of them are in a position to pay for daily caregiving but cannot find suitable carers. In addition, families such as these are also willing and able to pay for respite care.

Individuals will be identified who are suitable to be trained as personal assistants to provide physical care, carry out basic treatment or therapy and provide companionship in the family's home. Families would then pay for this service. As well as providing a solution to care needs, this scheme would also provide additional employment opportunities and a wage for potentially vulnerable members of society – perhaps migrants from rural areas, widows/single mothers, etc.

This approach will involve setting up a company registered in India. The company will be run along the lines of a social enterprise and will raise the standards of caregiving, training professionals who

will provide an invaluable service. Over a period of time, the money generated from this approach will contribute to the funds required for the advocacy and day centre approaches.

3. Day Care approach

This approach will be focussed on slums or townships.

Primary carers, usually mothers/wives/daughters, are unable to work as they need to care for their child/ husband/ parents who is sick or disabled. The concept is to set up a 'daycare' setting where the cared- for individual can go during the day and be looked after – given their medication, fed, stimulated etc. This would be staffed by interested individuals – either caregivers themselves or members of the local community. They would receive training and a stipend – contributed to by the families of those being cared for.

This would be a local community venture and the physical space would need to be provided by the local community leaders, local government or NGO/faith based organisation.

Adapting to different contexts

In India, there is a strong emphasis on community development and sustainability amongst the organisations I would be partnering with. They are particularly well placed to initiate the Advocacy approach.

In South Africa, the hospice movement is well established and provides daily and long term caregiving opportunities. The key needs in South Africa therefore are the Advocacy approach and the Day Centre approach. By developing these strands of work, Carers Worldwide can complement the existing situation and add invaluable support to carers, particularly in rural areas and townships.

In this way, I see the two programmes complementing each other – India is strong on the development approach and sustainability, and South Africa has capacity in research and the experience of the hospice movement. The potential for links between the two countries is exciting.

Carers Worldwide will sensitise local organisations, NGOS, international NGOs and governments to the needs of carers. Our aim is to enable these bodies to include carers into their existing programmes and to initiate additional activities to meet the needs of carers at all levels – emotional, physical, social and economic.

Enica lives in a small shack in a village in Limpopo Province, South Africa with her husband, three children, two orphaned nephews and her mother.

Her mother suffered a stroke a year ago, which left her paralysed, unable to communicate and dependent for all her daily needs. She requires round the clock care and this falls to Enica. Her husband supports her when he can, but he is out much of the day, looking for work wherever he can. Her sister was infected by HIV and died 3 years ago. Her remaining sister offers no support.



Enica finds herself with little time for her children and none for herself. She is unable to find employment and leads an increasingly isolated life. The burden of caring with no respite has taken her toll on her physically and at times she finds herself unable to eat or sleep.

"I don't have a choice but to lead life and there is no one to talk to."



Carers Worldwide can work with local community based organisations to support carers like Enica.

One activity is the setting up of networks of community carers who provide care in a central location – the day care approach. Enica could take her mother to the centre where she would be well looked after and stimulated.

Enica would be able to take up employment, accessing livelihoods support from the local CBO if required, thereby adding to the family income and supporting her children through school.

Working outside of the home would provide Enica with much needed social contact and start to restore her self esteem.

Through the CBO's advocacy approach, Enica would meet other carers and have the opportunity to share her experiences, realising that she is not alone.

Outcomes 3 and 4 – Next Steps

Outcomes 3 and 4 have been combined into the following section which details proposed establishment of Carers Worldwide, a registered charity which will work on addressing the situation of carers in developing countries.

Based on the issues identified during the research, I am proposing the way of working described above. In order to achieve this, I have developed a business plan, the main elements of which are detailed below. At every step, my work is guided by Carers Worldwide's vision, mission, guiding principles and strategic objectives.

Vision:

That throughout the world all carers' are recognised, respected and valued for their contributions to the society.

Mission:

To enable carers, service providers, policy makers and other stakeholders to identify and respond to the needs of carers in the community, whilst maintaining a balance between these and the needs of the person receiving care, ensuring that both are valued equally.

Guiding Principles:

1. *Carers are acknowledged, respected and valued.*
 - a. Carers are valued and respected for their contribution to society.
 - b. The diversity of carers, both in terms of their demographic (age, gender, cultural identity, sexual orientation, etc.) and their needs is recognised and addressed.
2. *Carers require support.*

Carers require support, particularly from the community. This will help them to achieve a meaningful quality of life which balances their caring for another with their need for self-care. Carers also require support to preserve or enhance their emotional relationship with the person receiving care.
3. *Carers have a voice.*

Carers have a voice in all decisions that affect them.
4. *Both people in the caring relationship are valued and their rights are respected.*

Empowering carers does not mean taking away the rights of the people who need care. A balance needs to be established to enable the needs of both people in the caring relationship to be met.

Priorities:

1. To test approaches which will meet the needs of carers in developing countries.

Carers Worldwide will test the approaches outlined under Outcome 2 with the potential partner organisations described overleaf.

2. To influence the policy debate and build evidence about carers in developing countries.

Carers Worldwide will contribute to shaping the policy environment, by providing evidence through research and entering into strategic partnership with relevant academic institutions.

3. To secure the sustainability of the charity and develop policies to ensure the effective management of its resources.

Carers Worldwide will develop a business plan and targeted fundraising strategy in order to generate and maintain funds to carry out its work.

4. To establish effective governance systems and human resource management

Through strong governance and the recruitment and retention of high calibre staff, Carers Worldwide will raise the profile of carers and effect positive long standing change.

1. Testing approaches which will meet the needs of carers in developing countries

Potential partners

Many of the groups and individuals I met with were keen to continue a working relationship in some way. I initially propose to follow up with several organisations and initiate programmes – indeed, after my visit a few organisations have already started including carers into their programmes and work plans.

INDIA

1. Samuha Samarthya

Based in Northern Karnataka, Samuha has undertaken community development programmes since 1987 with a special focus on vulnerable people, including people with HIV/AIDS and disability. 'Samarthya,' the disability unit of Samuha, has been working through self-help groups and community-based organisations of people with disabilities 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 3700 people with disability or mental illness in 3 districts – Raichur, Koppal and Karwar.



Carers meeting at Samuha Samarthya

2. SACRED (Social Action for Child Rehabilitation Emancipation and Development)

SACRED is a non-profit, social, secular voluntary organization, which is committed to the most deprived and under privileged sections of the society. The main aim of SACRED is to equalize disabled people alongside the able bodied and to encourage their active participation for their own development.

SACRED started work in 1997 with 2 villages and later expanded to 40 villages of Anathapur district and 56 villages in Kurnool district. They are currently working with over 1200 people with disability or mental illness.

3. Association of People with Disability

The Association of People with Disability (APD) is a Bangalore based organisation working since 1959 for children, youth and adults with various types of disabilities – primarily those with physical disability, cerebral palsy, spinal cord injury, development delay, and speech and multiple disabilities. Over the last 50 years APD has been working with people with disability to empower them to become contributing members of society and lead a life with self-esteem and dignity. At any point of time, APD creates a positive impact on over 20,000 people.

See Appendix 3 for maps detailing location of India potential partners

SOUTH AFRICA

1. The Highway Hospice Association

The Highway Hospice is one of South Africa's first Hospices and is situated in Sherwood, Durban. The Hospice provides a service designed to improve the quality of life for patients with a terminal illness and support for their families. It serves the eThekweni Municipality, 1.5 million.

There is an 8 bed inpatient unit where patients are admitted for pain and symptom management. When a patient has these needs met, they can then return home. There is also provision for respite when patients come into the unit for a short period of time to give their families a break. In addition, it receives approximately 750 patients per month. Nurses visit patients in their homes and are supported by a group of trained volunteer caregivers.



Family carer meeting at Umlazi, a township outside Durban

2. Zimele

Zimele primarily targets women who are heads of households and have the ability to impact multiple generations of children. Zimele strives to teach a value system that respects life and to change mindsets as this is the key to battling the huge challenge posed by the HIV/AIDS pandemic. Zimele (meaning 'I am standing on my own two feet' in Zulu) strives to make each community self-sufficient by building them to the point where they can sustain themselves.

Since its founding in 2006, Zimele has empowered over 1,200 women with the skills, resources, and support networks to build a brighter future for their families and communities. In 2011, they worked with 700 women in three communities of KZN province. By 2014, they will be expanding into two new communities to reach a total of 1,200 women per year.

3. Ethembeni

In November 2000, the Howick Community Church began a ministry to the community of a settlement called Mpophomeni in the KZN Midlands, specifically aimed at caring for those who are dying alone, hungry and without hope. Of the community of 30 000 people, more than 80% are unemployed and more than half are infected with HIV.

Ethembeni, means 'Place of Hope', and has the following mission statement: 'To provide spiritual, emotional and practical assistance to families affected by HIV & AIDS in the Mpophomeni area through the provision of home based care, family support with a focus on vulnerable children and residential care for terminally ill people.'

Each week, over 120 families are helped by over 40 carers and 20 volunteers.

OTHERS

1. The **Health Ministry of KZN Province** is keen to collaborate and this would have a major impact on sustainability as well as future policy and resource allocation.
2. **Professor Crick Lund** of Cape Town University is interested in researching the following areas: impact of caring, specifically in relation to mental health, and impact of livelihood activities in improving the life of the carer.
3. **The National Institute of Mental Health and Neurosciences (NIMHANS)** in Bangalore, India is keen to be involved in research, specifically looking at the profile of carers, impact of caring and development of carers' assessment tool.

2. Influencing the policy debate and building evidence about carers in developing countries

Influencing the policies of well established organisations currently working in the field of disability, HIV/AIDS, mental health, chronic illness and the elderly to include carers and their needs into their programmes is fundamental.

Bridging the gap between policy and practice by conducting action research on programme outcomes and promoting caring for carers' policies would be a key way of moving the change process forward.

Through collaborative research, Carers Worldwide will:

a) Develop a clear picture of caregiving through data collection

In order to provide services to carers, a true picture of caregiving in the form of a comprehensive data collection programme would be needed. This would initially be carried out by Carers Worldwide and its research partners through its partner organisations, but would also involve influencing larger organisations to include this information as standard in their own ongoing data collection. As well as collecting the data, it will be important to analyse data and disseminate findings about caregiving.

b) Develop a research agenda for caregiving including knowledge transfer mechanisms

The development and implementation of a comprehensive and relevant research agenda would generate and transfer knowledge about all aspects of caregiving, including health care outcomes, impacts of policies and services, best practices, economic dimensions and psychosocial aspects of family caregiving. Research and knowledge transfer would in turn lead to policies and programmes that enhance the quality and sustainability of care.

3. Securing the sustainability of the charity and developing policies to ensure the effective management of its resources

To develop Carers Worldwide as an effective and influential force, with the support of the Board of Trustees I will address the following:

- Strategy
- Policy
- Fundraising
- Networking into northern structures

Fundraising

Without funding, putting the Carers Worldwide model into practice will not be possible. Business plans will be developed as a means of approaching various trusts and foundations as well as individual philanthropists.

It is hoped that a part time fundraiser can be employed in the UK to raise funds. The fundraiser would also be involved in promoting Carers Worldwide with other organisations. At the start, funding will be secured centrally and allocated accordingly to those involved in its delivery. As the programme goes on, in-country partners will be encouraged and supported to seek funds for the aspect that they are responsible for. This strategy will ensure that skills remain with the partner organisation, reduce the dependency on Carers Worldwide and increase the likelihood of the continuation of the programme.

Fund raising will be focussed on the following areas:

- Website for individual giving
- Donor database for management of donors
- Research into sources of funding
- Writing up of an early case for support
- Submitting applications to institutional sources
- Talking to board members and other supporters about their role in fundraising

Currently, the Carers Worldwide logo and website are under development. Brochures, promotional material, case studies etc are being written up to support fundraising activities and general profile raising.

4. Establishing effective governance systems and human resource management

In order to bring about long term change for carers in developing countries, Carers Worldwide will require effective and robust leadership. This will be achieved through:

- Governance
- Leadership
- Worldwide management

Initially, the lead will come from the UK. It is hoped that, in time, leadership and worldwide management will be taken on by personnel within the developing countries.

Governance

The first promoters meeting was held on 3rd April 2012 and the three promoters were officially appointed as Trustees.

The **founding trustees** of Carers Worldwide are:

Chris Underhill



Chris has spent 37 years committed to assisting marginalised people either in the UK or overseas. He has started up, managed or been a trustee of charities specialising in championing new ideas and innovations and has founded and directed three charities:

- Thrive (formerly Horticultural Therapy), a UK based charity working with disabled people and medical professionals in horticulture, gardening and agriculture;
- Action on Disability and Development (ADD), a development agency targeting disabled people in the third world;
- BasicNeeds – new initiatives in mental health and development working with mentally ill people in the third world.

Chris was awarded the MBE in 2000 for his work in international disability.

Siân Edwards



Siân has twenty years experience working in the voluntary sector, almost all of it in long term international development.

Through appointments with Action Aid, Action on Disability and Development and BasicNeeds, plus seven years of freelance work, she has supported work throughout south Asia, and in more than a dozen countries in Africa, the Middle East and the Pacific rim. This has included periods living in Bangladesh and Uganda.

Siân has been Director of the Andrews Charitable Trust since 2006.

Sue Taylor



Sue began her career 25 years ago at the accountancy firm KPMG. She worked for Royal Dutch Shell PLC for 11 years, then moved to Shell Marine Products Limited where she was the Credit Manager before taking the role of Financial Controller. Following a career break she worked as the Finance Manager of Land Design Studio, an architectural design company.

Since 2009, Sue has been Management Accountant of Iveagh, a private investment house established by the Guinness Family.

Registration as a charity

Carers Worldwide in the UK is currently working towards registering under the Companies Act and then being registered with the Charity Commission. To date:

- The Charity objects and Trust deed are finalised
- CRB checks have been done for the promoters and executive director of the Trust
 - Chris Underhill
 - Sian Edwards
 - Anil Patil

Leadership

As Founder and Executive Director of Carers Worldwide I will be responsible for the strategic management and leadership of the whole organisation and accountable to the trustees. I will contribute particular skills in development – both of programmes and the organisational structures to support them.

In particular, I will be focussing on the following:

- Supporting the initiatives of the programme
- Developing strategy, research and policies
- Ensuring that the design and development of the work is properly managed
- Promoting the organisation both in the UK and abroad
- Following up on fund-raising leads particularly with regard to programme fund-raising.
- Governance

Worldwide management

As Carers Worldwide develops, personnel in developing countries will take on an increasing role in senior positions, shaping policies and implementing aspects of the programmes. For example, senior researchers will be based at academic institutions; the advocacy lead may be from India, and so on.

Overall management will continue to be headed up by the Executive Director, wherever he may be based, and guided by the trustees. It is also envisaged that future trustees may come from in-country.

Through the Carers Worldwide Forums, local stakeholders will be involved as advisors, whose expertise will feed into shaping strategy, policy and practice.

SRINIVAS AND GOWRI

Srinivas lives in a small village in South India. Four years ago he sustained a spinal cord injury which left him paralysed from the waist down. His wife subsequently deserted him, leaving only his 9 year old daughter Gowri to take care of him. They were thrown out of the family home and found themselves living in a cowshed, sleeping on the floor.

Gowri had no support from family members or the community and soon had to abandon her studies at school. She was responsible for cooking and cleaning as well as attending to her father's physical needs. Through Gowri's determination to help her father, Srinivas gradually became able to do a little more for himself and even move himself around in a wheelchair.



However, as time went on, Gowri became more and more withdrawn from society and angry with her situation. It was becoming increasingly hard for her to cope with caring for her father, at the same as she was developing as a young woman.

Samarthya, a local group working with people with disabilities came to hear about Srinivas' condition. They took him to specialist doctors in Bangalore and were able to access a temporary house through a Government scheme. However, nobody had thought to look at the needs of Gowri.

When Anil Patil, the Founder and Executive Director of Carers Worldwide, visited he found a young woman resentful of the burden placed upon her and struggling to cope with her own needs, as well as those of her father. She had no privacy. There was no toilet in their house and she had no female support to guide her. Anil worked with the staff of Samarthya to help them understand that Gowri's needs were just as important as those of Srinivas. Indeed, if something was not done to support Gowri soon, there was the risk that she too would abandon Srinivas.

As a result, a package of support has now been put in place for Gowri. Female staff from Samarthya visit her regularly to provide emotional support and advice. A trained counsellor is available for her to talk to in confidence. Funds have been raised to construct a toilet room at the back of the house, giving Gowri the privacy she needs.

Meeting Gowri now, you can see a young woman regaining her confidence in life and trust in others. She is returning to school part time. Her life remains difficult, but knowing that she has someone to turn to and a little time for herself means that she is better able to deal with the challenges faced by her and her father.

CHILD CARERS

Like Gowri, there are many child carers in India. They face the loss of their childhood and their education. The expectations on them are so great that they often become physically unwell themselves and withdraw from society. Most of them have nobody to turn to. Simple, low cost solutions such as those provided for Gowri make a huge impact but are all too rare.

Carers Worldwide aims to sensitise organisations working with the sick, elderly and disabled about the needs of carers and to demonstrate that a few simple actions can have profound effects.

APPENDIX 1

ORGANISATIONS AND INDIVIDUALS VISITED IN INDIA

- Samuha Samarthya, Karnataka
- SACRED, Andhra Pradesh
- Association of People with Disability, Bangalore
- BasicNeeds India, Bangalore – new initiatives in mental health
- Sanghamitra Iyengar, Samraksha, Bangalore – working with HIV/AIDS
- Dr Nirmala Sreenivasan, ACMI, Bangalore – policy and advocacy on mental health issues
- National Institute of Mental Health and Neurosciences, Bangalore
- Pallium India, Kerala – palliative care
- Vidyasagar, Chennai – working with cerebral palsy, autism and multiple disabilities
- Dr Thara Srinivasan, SCARE, Chennai – working with schizophrenia
- Dr Radha Shanker, Psychiatrist, Chennai
- Autism Society of India, Bangalore
- Vandana Bedi, Spastics Society of Northern India, Delhi
- Kalyani Menon, Delhi – UNDP gender perspective
- Poonam Natarajan, National Trust, Delhi – advising Government on multiple disabilities
- Sanjeev Sachdev, Delhi -
- Javed Abidi, Disabled People International, Delhi
- Dr Kamraj, Delhi – National Advisor on Leprosy for WHO
- Mathew Cherian, Help Age India, Bangalore
- Dr Kishore Rao, Karunashraya, Bangalore – working with life limiting conditions
- Paraspara, Bangalore – working with community issues in slums
- Dr Sreedevi, Richmond Fellowship, Bangalore – halfway home for people with mental illness

ORGANISATIONS AND INDIVIDUALS VISITED IN SOUTH AFRICA

- Highway Hospice, Durban
- South Coast Hospice, Port Shepstone
- Headway Hospice, Durban
- Zimele, KwaZulu Natal Province
- Enthembeni, KwaZulu Natal Province
- A centre that serves (ACTS), Amanzimtoti, KwaZulu Natal Province – working with HIV/AIDS
- Dr S Mdwani, Health Ministry, KwaZulu Natal Province
- Diane and Simon, Durban – caring for a daughter with a brain injury
- Ann and Shastri Naidoo, Durban – working with HIV/AIDS orphans
- Soul Action, Durban – network of faith based organisations working with HIV/AIDS
- MK Umbrella, Limpopo Province – working with HIV/AIDS
- Sister Dorcas, Health Ministry, Limpopo Province
- Save the Children, Pretoria
- Ann and Peter Nolan, Pretoria – DFID representatives
- FHI 360, Pretoria – community development initiatives
- World Vision International, Johannesburg
- Cotlands, Johannesburg – children’s centre
- Professor Crick Lund, Cape Town University
- Dr Richard Harding, Cape Town University
- Dr Jill Oliver, Cape Town University
- Cape Town Mental Health Society, Cape Town
- Brian Gannon, Child and Youth Care Network, Cape Town
- Chaeli Campaign, Cape Town – working with disabled children
- Hospice and Palliative Care Association, Cape Town

APPENDIX 2

PROCESS OF MEETINGS

Meetings with carers

During the course of the India and South Africa visits, I met with over 400 carers looking after people with disability, mental illness, those affected by HIV/AIDS, life limiting conditions or old age. Most were family carers but in South Africa I also met community caregivers. These meetings were critical to my understanding of the issues affecting carers and their needs. I wanted to hear their experiences first hand – their challenges, difficulties, but also triumphs. I also knew that they would have their own ideas for improving their lives, both individually and as part of a group, and I wanted to hear these too. It was important that the meetings be a 'safe place', where openness and sharing were encouraged and the participants felt comfortable to share their stories. At times, what we heard was distressing and harrowing, and carers learnt that they were by no means alone in their struggle. However, there was an overwhelming air of positivity as carers felt supported and empowered by the process of sharing, so much so that several organisations have now gone on to set up further support meetings with groups of carers.

Meetings generally followed the same format, although within this there was a flexibility to follow particular strands of discussion that arose from group to group.

I started by introducing myself and providing background information as to why I was there and some details about carers in general. Group members were invited to introduce themselves and we set ground rules, including rules about confidentiality and permission to take photographs to document the process.

There then followed a series of group exercises where participants split into smaller groups and undertook the following exercises:

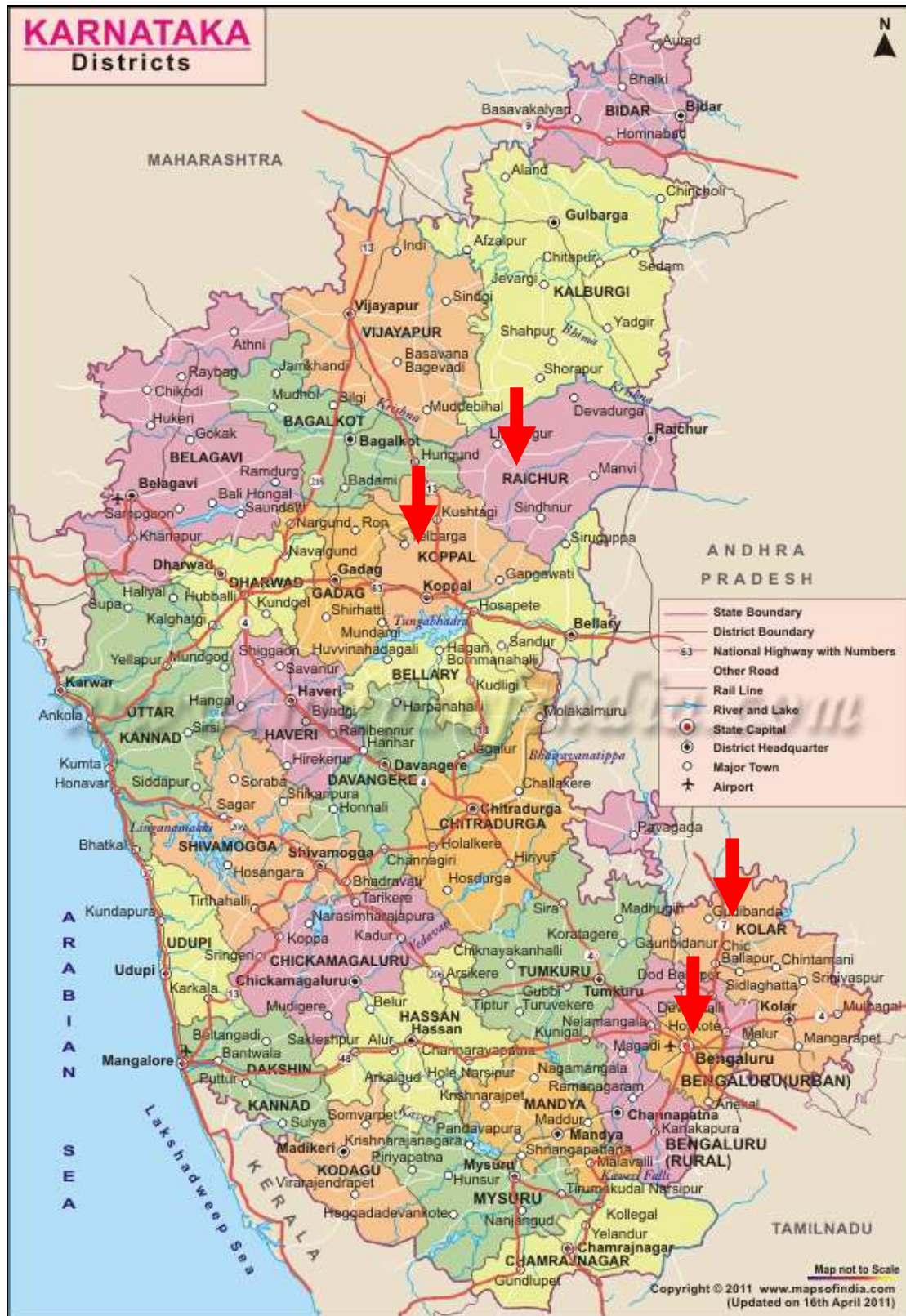
- Constituency mapping to bring out the key relationships in the life of a carer
- Discussion about the needs of carers and the problems faced by carers
- Discussion about what they would like to happen next

The discussions were documented on large sheets of paper, either in English or in their regional language. After each exercise, the small groups fed back their discussions to the larger group and there followed opportunity for comments and observations to be made on each group's contribution. This process was repeated for each of the three exercises. As a conclusion to the meetings, I summarised the process and the outcomes of the discussions. I made some initial observations to the groups and also the organisations facilitating the meetings, before helping them to outline potential next steps.

Meetings with senior management staff of NGOs/INGOs, government agencies and academics

During these meetings, I explored:

- the level of awareness and recognition of the contribution of carers and the consequences of continued caregiving (eg. loss of education, employment, social contact)
- existing provision for carers, such as social protection
- extent and range of the issue (numbers of carers, existence of child carers, profile of carers with regard to gender, economic status etc.)
- any research carried out around the impact of caregiving
- current levels of experience and /or expertise of working with carers
- the place carers have within the development agenda (eg. linking with Millenium Development Goals)
- opportunities for continued collaboration



ANDHRA PRADESH POLITICAL MAP



APPENDIX 4

Brief bio of Anil Patil, Founder and Executive Director of Carers Worldwide

I have over 16 years experience in the international development sector, as a grant-maker, Trustee and development worker, the latter within both private and non-governmental organisations.

I am a veterinarian by training and prior to coming to the UK in 2003, I worked in the Indian NGO sector for eight years, both at the grass roots and national level, in the areas of animal husbandry, and developing sustainable livelihoods. This included working with individuals to encourage and facilitate to set up their own community-based self-help groups. During this time I also had the opportunity to work with a range of local groups and partner organisations in South India on a variety of initiatives including disability (especially mental health), primary health, HIV/AIDS and education. Many of the groups I worked with were from the more vulnerable sections of society: children, women and people with disabilities.

In 2004 I graduated from University College, London with a Masters Degree in International Disability and Development. I then began work in the UK as Project Manager of the Wellcome Trust's "Livestock for Life" global grants scheme and in 2007 joined The Tubney Charitable Trust, working to deliver and develop the Trust's Farmed Animal Welfare programme. For the past five years I have been a Trustee of BasicNeeds, an international development charity working to transform the lives of mentally ill people in Africa and Asia.

I am an innovative thinker with great ambition, drive and a "can do" attitude. I am skilled at building strong and effective networks and have extensive experience in delivering positive change for the public benefit in the fields of community mental health, development and farmed animal welfare as well as community-based interventions in developing countries. This experience, which is strengthened by my strong professional and personal interest in disability, means that I am well versed not only with developing integrated policy but also turning it into reality.