BasicNeeds
BasicRights

right to be treated to be treated right

BASICNEEDS REVIEW

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The BasicNeeds Review

Contents

vision and mission

DHARSHANA KARUNATHILAKE

We are grateful to Molecular Products Group plc for their kind support of this review (see page 32)

Cover photograph: Chris Underhill

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DHARSHANA KARUNATHILAKE

Revealing the truth about mental illness:
a consultation workshop, Sri Lanka

Our vision is that the basic needs of all mentally ill people throughout the world are met, and their basic rights are respected.

Our mission is to initiate programmes in developing countries which actively involve mentally ill people and their carers and enable them to realize their basic needs and exercise their basic rights.

BasicNeeds addresses both people's mental illness and their poverty to enable the achievement of a sustainable recovery.

Our work is based on the philosophy of building inclusive communities, where mentally ill people—through development—realize their rights.

Basic Needs, Basic Rights

Inclusion

The work described in this review has come about because we have listened to mentally ill people, their carers and the greater community that they live in. This has led us to design and manage inclusive programmes that place mentally ill people firmly in the mainstream of development. Whatever progress we have made can be directly traced to this initial consultation process.

right to be treated to be treated right

From the Chair of Trustees

BasicNeeds is making itself noticed at an increasingly influential level, and this gives us greater scope to effect change. There has been real success in the field of fundraising which is a considerable tribute to all our colleagues who work together to put together what are often very complex proposals.

This year has also been one where we have made new appointments to develop our infrastructure ahead of capacity. It was always our intention to outsource where possible to colleagues abroad and keep the UK operation trim. However, I am pleased to say that the appointment of Mike Paul as our first Chief Operating Officer will make a real difference, enabling other colleagues to further develop the work and systems of BasicNeeds.

I would like to thank all our colleagues, supporters, and associates who make our work possible. Lastly, but most importantly, it is the encouragement and enormous support from the people and families with whom we work that make it all so rewarding.

Amelia Fitzalan Howard

messages

From the Chairperson, BasicNeeds India Trust

When people with mental illness and their carers first talk to BasicNeeds and our partner organizations it is clear that their most pressing concern is the need for treatment. But it isn't long before further consultation brings out the other, equally important, concerns—stigma, isolation, and the need for social and economic well-being.

Despite a number of difficulties at different levels, BasicNeeds has made considerable headway by creatively addressing these concerns. We have brought together community-based organizations and larger institutions responsible for and concerned about mental health. We have successfully co-opted local doctors and district hospitals in our efforts. Committed psychiatrists have trained field staff and consulted with people. It is thus becoming more and more possible for people to regularly attend health camps for diagnosis, assessment and medication.

The interaction between communities, organizations and institutions has also enabled the wider appreciation and application of the Mental Health and Development Model on which our work is based. The model acknowledges the right of mentally ill people to consult and be consulted and goes beyond diagnosis and the provision of treatment to focus on mental health in a community setting.

The many challenges that mentally ill people in poor communities face must be addressed within the socio-economic context of their lives. It is, primarily, the commitment and energy of our partners who work in the field that is beginning to make change possible.

Valli Seshan

From the Founder Director

Welcome to this edition of the BasicNeeds Review. In my work I regularly come upon stories about mentally ill people who are chained to the family house to stop them from wandering. Indeed I have been told that it is better for a person to remain chained in all weathers outside their home than to go far from home to hospital to be over-medicated amongst strangers. This is no choice at all. It is an argument of despair.

Our programmes show clearly that with quite modest funding so much can be done to redress the arguments of despair and to build good practice where there was none before. Since we started our field operations in September 2000 we have laid great emphasis on the practical nature of our work. The idea has been to grow the organization so as to lay a pattern of programmes in different settings and countries, permitting us to speak about mental health and development with authority and experience.

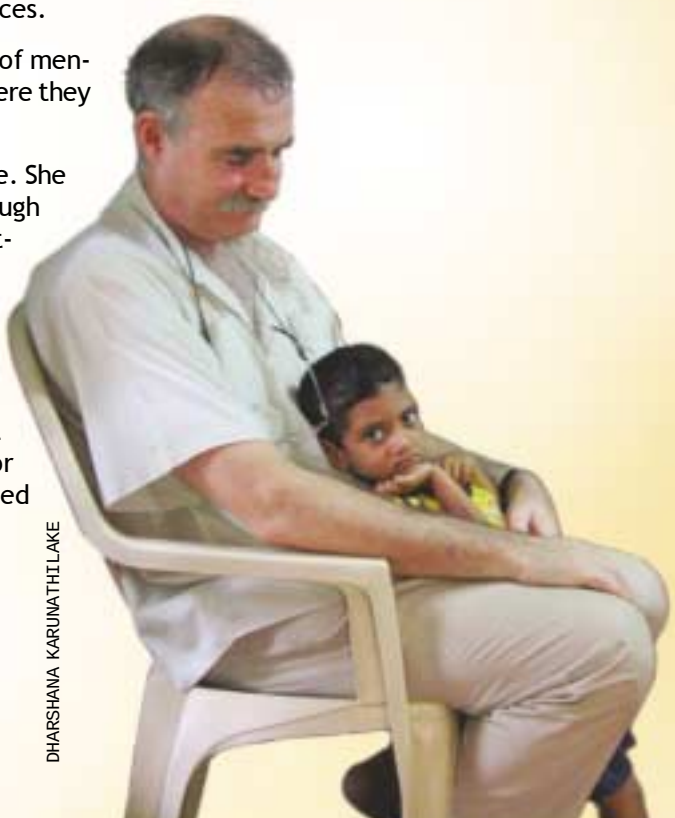
In South India we have positioned ourselves by resourcing an alliance of six organizations now gearing up to serve mentally ill people and their families. Using the collective power of partner organizations has proved crucial to the way we work as demonstrated in our Indian work. In Sri Lanka we are managing a vibrant volunteer-run programme in the south of the island, and a horticultural therapy programme as a way of helping long-stay patients to leave hospital. Our first programme in Africa, in Northern Ghana, has brought kindness-in-action to a landscape bereft of both for mentally ill people. The programme in Uganda is just beginning, but in Mtwara, the poorest region of Tanzania, we have already responded to the Government's invitation to launch two programmes which are now under way.

The difficulty for Governments to fund the mental health sector and how we fund ourselves are related in a thought-provoking way and we pay tribute to some of the people and institutions who have helped us so much, including the generous sponsors of this review. In order to continue our strategic growth we have developed a policy and research programme managed from India, a project management service managed from Sri Lanka, and have appointed a Chief Operating Officer, Mike Paul, who has done a great deal to ensure that systems are in place for the continuing demand on our services.

In this review we highlight the right of mentally ill people to have treatment where they most need it.

I met the woman in our cover picture. She was waiting for treatment true enough but more importantly she was waiting for justice. Terribly abused all her life, finally, treatment is available to her. After treatment will come the search for livelihood and then her struggle for rights. This is what touches me so powerfully about our work for we are all working for the right to be treated to be treated right.

Chris Underhill



DHARSHANA KARUNATHILAKE

right to be treated to be treated right

right to be treated ...to be treated right

Chris Underhill and Shoba Raja

Mental illness was estimated to account for about 12.3 per cent of the global burden of disease in 2000[1] and this is projected to rise to 15 per cent by the year 2020, proportionately higher than that for cardiovascular diseases[2].

A study conducted by the Global Burden of Disease project (sponsored by WHO and the World Bank and based at the Harvard School of Public Health) shows that the burden of psychiatric conditions has been heavily underestimated. Of the ten leading causes of disability worldwide in 1990, measured in years lived with a disability, five were psychiatric conditions. Unipolar depression is the single leading cause of disability worldwide. Altogether, psychiatric and neurological conditions accounted for 28 per cent of all years lived with disability[3].

Piyasena, a participant in our Sri Lanka programme, talks about his recent time in mental hospital: 'Hope is a good thing, you know. Hope will make us free. Doctors visited us once a week. And everybody was waiting for the day when they would be discharged. But only once in a blue moon did anyone succeed. It was a bad place. If you go there it's not easy to come out of it. Society will label you as a crazy person and they will try to keep you inside as long as they can.' He had his own way of dealing with it. 'Hope will make you free. Fear will make you a prisoner.'

A participant in northern Ghana describes how he had been feeling: 'Not feeling like a being—I am nothing among my family members and the community I live.'

To be heard is to be recognized. To be recognized is to gain hope. Hope will make you free.

The power of listening to people who have never been invited to speak is significant. This becomes evident, again and again, at every contact we make with mentally ill people no matter in which country. *Active* listening to their fears and their hopes. Just one way in which our model for mental health and development begins to support mentally ill people and their carers (refer box on page 7).

Usually, our first meaningful contact with people with mental illness is during a 'field consultation'.

Who attends a field consultation? Mentally ill people, their carers, voluntary and community organizations, community members, representatives from Government health and other services, BasicNeeds staff.

DHARSHANA KARUNATHILAKE

Some mentally ill people come to the meeting in chains. Their families timid, frightened, exasperated and ashamed all at once. Faces tight and drawn.

Some mentally ill people have been incarcerated for years. Sometimes right under the nose of the community but unknown to them: Fear will make you a prisoner. Others again have been the target of cruel humour for years: Not feeling like a being ...

Steady gains:
Piyasena demonstrates progress at a field visit held for medical officers of mental health

MODEL FOR MENTAL HEALTH AND DEVELOPMENT

Capacity-building: Supporting mentally ill people and their carers to actively participate in consultation workshops and self-help groups; institutional strengthening of community-based partners on a range of aspects required for sustainability.

Community Mental Health: Mechanisms developed for easy access to mental health services by mentally ill people.

Promoting sustainable livelihoods: Once feeling more stable, many mentally ill people return to the work that they were doing before they fell ill. After a while some of the participants in the programme join formal savings and credit schemes along with other members of the community.

Research, Policy and Advocacy: Understanding the context within which the programme operates, with the involvement of all the stakeholders, so as to build an information base to represent people who are mentally ill. A series of life stories, with the voices of mentally ill people at the centre of the narrative, has been developed.

Programme Management and Administration: Administering the programme with the active participation of partners in planning, implementation and monitoring.

1 World Health Organization. *World health report 2001*. Geneva: WHO, 2001, p.25

2 Murray CJL, Lopez AD. *The global burden of disease*. Vol 1. A comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990, and projected to 2020. Cambridge, MA: Harvard University Press, 1996 Summary of Volume 1, Chapter 7 (p. 325-395), p.37

3 Murray CJL, Lopez AD. *The global burden of disease*. Vol 1. A comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990, and projected to 2020. Cambridge, MA: Harvard University Press, 1996 Summary of Volume 1, Chapter 4 (p. 201-246), p.21

When people get together at a meeting what do they want? Like an avalanche of need the voices are heard. **Mentally ill people** want to get better, recover, work, earn, contribute to their family, marry, have a family of their own.

They want to leave their illness behind. Lakshmana from a village in South India clearly wants this and much more: 'I want to study. I want to be educated. I want to work. I want to stand on my own feet. I want to have my own silk weaving machine. Can you get me a job? A real job—somewhere?'

The families want medicines, a way of coping, to understand and to be understood for the calamity that they feel has fallen on them. They often want to send the person far away for good. Only gradually do they become convinced that there are solutions that could be accessed locally.

They are desperate to release the carer back to earning. 'It is a long distance to go by bus [for treatment] and there's no money. If he is told to go alone, he wants me to go with him. We don't have money for two persons. One has to earn something to be able to pay!' says Hanumakka talking about her son at a group meeting in rural India. 'There is no money to attend the monthly camps[4]. I have to work in the field. No one has peace of mind— thinking about work and these problems.' At times to release the carer the mentally ill relative is shackled: locked down.

Mental health professionals seek treatment as a significant means of achieving positive change and reducing stigma. Many of them also see it as a means to reduce the burden of care for the families of their patients.

They are marginalized by association with mental illness. They often feel alone and find it very hard to challenge the stigma implicit in policy norms. 'We need to go from P3 to P1,' a chief psychiatrist told us recently. Our faces looked a little blank. 'P stands for priority' and he went on: 'P1 is for highly communicable diseases like HIV/AIDS, P2 is for mothers and children and P3 is for all non-communicable diseases of which mental health is a small, a very small, part. When P1 runs out of money 'they' raid P3.' A brutal lesson in national health policy.

All three key stakeholders share their perceptions that treatment is a priority need. However, this clarity of purpose does not feature in existing legislation, policies, programmes and resource allocations related to mental health issues—either to overall policy or the policy of treatment on its own. Generally, these policy arrangements are not linked and thus do not form a coherent whole. Indeed forty per cent of countries have no mental health policies and twenty-five per cent have no legislation in the field of mental health at all.

Forty per cent of countries have no mental health policies and 25 per cent have no legislation in the field of mental health. Services also show huge international variations with one-third of people (33 countries with a combined population of two billion) living in nations that invest less than one per cent of their total health budget in mental health. More than two-thirds of the world's population (68 per cent), the majority of whom are in Africa and South Asia, have access to less than one psychiatrist per 100,000 of population. While the burden of neuropsychiatric disorders out of all disorders is 12.3 per cent, the median mental health budget out of the total health budget is 2.2 per cent world wide[5].

From institution to community:
outreach clinic team distributing drugs at Gusheigu

Rachel Jenkins[6] observes: 'In developing mental health policy, it is important to include consideration of stigma about mental health issues and mental illness. As well as the impact on the individual with mental illness, stigma results in a lack of attention from ministers and the public, which then results in a lack of resource and morale, decaying institutions, lack of leadership, inadequate information systems, inadequate legislation, and inadequate attention to key public health committees.'

Inusah, from Ghana: 'I faced so much isolation from both the family and friends. Anything I said was seen not to make sense even when I am not sick. No one took me serious when I want something or when I said I am feeling better.' Stigma operates not just within what is considered 'ignorant' families or communities. It contributes also to the faulty approach, the seeming indifference in formulating or implementing policy for treatment of mental illness.

Hope is a good thing, as Piyasena so eloquently puts it, but mentally ill people manifestly deserve more. Without treatment it is often very difficult to go forward. Poverty brings no treatment and no treatment is poverty— dreary, grinding, poverty. Unwillingness to provide treatment is the denial of a basic right. When policy and practice combine in accessible delivery, freedom[7] comes. Most participants, once treated, go back to work or provide support to the family and its livelihood. This is one of the most effective ways of reducing stigma. The right to be treated so as to be treated right.

4 A form of extending specialist treatment into rural areas, in India particularly, is the so-called 'camp' system where psychiatrists from urban centres go to examine and treat at a specified date(s).

5 World Health Organization. *Atlas: country profiles on mental health resources 2001*. Geneva: WHO, 2001

http://www.cvdinfobase.ca/mh-atlas

6 Rachel Jenkins, 2003, Supporting Governments To Adopt Mental Health Policies, World Psychiatry, 2:14-19

7 After Amarthya Sen, 2000, "*Development as Freedom*", Oxford University Press

India

Programme Manager:
D. M. Naidu

'People used to call me *Mad Chowdappa* and drive me away from the temple. Today I serve as poojary [priest] in the very same temple.'

Chowdappa of Nagireddypalli (SACRED project area)

Almost 70 per cent of the people of India live in rural areas and a third of the country's rural population live in conditions of extreme poverty. Under these circumstances, the needs of people with mental illness are easily—and largely—overlooked.

India faces the challenge of 60 million people with minor and major mental illnesses. Professional resources and

Mapping resources: **presenting views at a review workshop**

Animation in progress: **consulting mentally ill people at a review workshop**

services elude the vast majority of people—mentally ill people continue to be victims of human rights violations.

Of crucial relevance to the issue of access to treatment is the prevalence of beliefs that attribute mental illness to demonic possession, witchcraft, or divine retribution for misdeeds in previous births. This leads to people seeking treatment from faith healers, or a total neglect of persons with mental illness.

An alternative resource base that's closer to the community. That's what people with mental illness so urgently need. And that's what BasicNeeds India is all about.

Our projects cover thirty-two districts—one in Andhra Pradesh, five in Karnataka, twelve in Tamil Nadu and fourteen in Bihar and Jharkhand.

We work with six partners in South India: the Narendra Foundation, SACRED (Social Action for Child Rehabilitation, Emancipation, and Development), GASS (Grameen Abhicrudhi Seva Sangha), SAMUHA, ADD India (Action for Disability and Development India), and Vidya Sagar. And in North India we work with the Nav Bharath Jagruti Kendra (NBJK).

Much of our work has depended on identifying and making the most of existing resources. NIMHANS (National Institute of Mental Health and Neuro Sciences) runs free monthly camps at Gowribidanur and Madugur for assessment, diagnosis, and treatment. SACRED and Narendra Foundation use this facility to access treatment for people in their project areas.

'This is good work. Earlier we had to go to Bangalore for treatment. Now we get treatment and medical facilities at our doorstep. By attending camps regularly our daughter has improved and the whole family is happy. We thought of it as a burden and stress earlier. It no longer seems so.'

Carer, on the work of GASS

Dr. Kishore of NIMHANS, along with a local doctor, provides free consultation services once a month to persons with mental illness in GASS project areas. Medicines are provided by GASS free of charge or for a nominal fee.

Treatment and some medication are available free of charge at the district hospitals and the Karnataka Institute for Mental Health in Dharwad. SACRED and SAMUHA negotiated with local district hospitals to access these services. SAMUHA also accompanies people to Dharwad for treatment.

Dr. Ajay, a private psychiatrist, provides free services and training to people in the SAMUHA project area in Koppal District. Dr. Mali Patil of the district hospital in Raichur volunteers his services for consultation and training.

The District Mental Health Programme camps conducted by Shrishti (an NGO), district hospitals, and private psychiatrists are accessed by ADD India for people from their project areas.

With the intervention of NHRC (The National Human Rights Commission of India), RINPAS (Ranchi Institute of Neuro Psychiatry and Allied Sciences) has now moved out into the community and conducts free treatment camps across Jharkhand. This process was facilitated by NBJK. No government facilities exist in the state of Bihar as yet.

Stakeholders in the area of mental health were brought together at a National Consultation organized in collaboration with the British Council in New Delhi. The outcome was an initiative to form a national-level mental health policy information network. The network will serve as a platform to influence policy in favour of poor people with mental illness.

'She has stabilized and become a responsible person, and is no longer a burden on the family. She also engages in earning for her livelihood and takes care of day-to-day expenses. We never dreamt of such a drastic change in her behaviour.'

Janardhan of BasicNeeds speaks of Amravathy—ADD India's Tamil Nadu programme

Sharing insights: consultation workshop

Celebrating improvements:
home visit by BasicNeeds members and partners

Our work has mobilized a range of people and organizations to be active in the field of mental health. This has made a significant impact on reach and impact.

Increased access to treatment has, to a considerable extent, resulted in the reduction of stigma. It has also improved awareness on mental health and provided relief to the carers of people with mental illness.

Basic Needs India's interventions began in 2001 with 200 people. Today we are working closely with approximately 2,600 persons with mental illness—and their families and communities are benefiting as well.

Over the past three years, the scope and reach of the programme has expanded. Significant among these is the broadening of the nature of our partnerships from direct partnerships with community-based organizations to include partnerships with larger NGOs who have their own networks.

Also of relevance is the health camp approach, which, in the absence of alternatives, serves to facilitate access to treatment. The awareness generated through the mental health camps and the visible changes in the people with mental illness has served to promote collaborations with other government and private resources for accessing treatment.

A recent development has been the extension of the programme to urban areas where poverty serves as a barrier to accessing treatment. The programme operates through NGOs working among the urban poor in Bangalore.

'We only attend to the treatment requirements of the patient. But mere medication is not sufficient. The other requirements which you fulfil like support to the person, carer and family on a regular basis are far more significant.'

Dr. Chakravarty, Director - RINPAS appreciating the work of NBJK

right to be treated to be treated right

sri lanka

Programme Manager:
Chintha Munasinghe

For a country with one of the highest suicide[1] rates in the world and recognized post-conflict problems[2], Sri Lanka's mental health infrastructure—in terms of trained personnel, hospital beds, community care facilities and social policies—is starkly inadequate. However, from the year 2000, the Ministry of Health, Nutrition and Welfare has made considerable effort to improve the accessibility of mental health services.

Angunakolapelessa Divisional Secretariat Division in the Hambantota district of the Southern Province covers 51 Grama Niladhari divisions[3] with 11,598 families whose main

'When we finished our 6-day practical training on mental health at the Mental Hospital, Angoda, some patients became friendly with us. Holding our hands they said 'Please sister, come again to be with us.' I still keep hearing it. Compared to them, mentally ill people living with us are lucky, because they receive treatment and care in the community.'

Lalitha, Member of Angunukolapelessa Mental Health and Development Volunteer Committee

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1 Suicide is interpreted by society in many different ways (e.g. jilted love). In fact it is substantially linked to demonstrable mental illness (WHO World Health Report, 2001).

2 JVP Insurrection in the South (1986 - 1989); North and East war between the government and the LTTE (1980 - 2001); increased anti communal riots, bombings and mass killings (1983 -2001).

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occupation is paddy and chena[4] cultivation. Even within Sri Lanka the area is infamous for its high rate of suicides and high prevalence of mental illnesses. It was severely affected during the armed conflict between government forces and southern rebels during the late 1980s.

BasicNeeds Sri Lanka's approach to mental health and development was to work first with a small community so that it would allow the programme to closely monitor the issues that challenge mentally ill people and their families. The Mental Health and Development Model of BasicNeeds, which was first developed and tested in South India, was used as a guide.

BasicNeeds started working with Navejeevana[5] in Angunukolapelessa in 2002, focusing on mentally ill people from five Grama Niladhari (GN) divisions[6]. Since then, the programme has served 207 mentally ill people from the project area and beyond, of whom about 50 per cent are from the villages of the project area.

The first consultation workshop was held in Thalawa South in September 2002, with much support from community leaders, to consult mentally ill people, carers and the community members. At the end of the day a village plan for social integration of mentally ill people was developed and a team of volunteers came forward to support the BasicNeeds-Navajeevana team. Interestingly, all the groups representing the five Grama Niladhari Divisions prioritized providing care and treatment in their localities. Education programmes on mental health, provision of opportunities to share problems, and livelihood options were also identified as areas that needed to be addressed.

Demonstrating strength:
Chris on visits model farm run by self-help group

3 The Grama Niladhari division is the primary level government representative unit in Sri Lanka, which is represented by the Grama Niladhari (Village Officer).

4 A type of cultivation method used for vegetable growing in semi-arid zone villages adjacent to forests.

5 Navajeevana is a non-governmental organization based in Tangalle, Sri Lanka, that runs a community-based rehabilitation (CBR) programme for people with disabilities. It provides centre-based as well as outreach services in physiotherapy, audio-testing and hearing support and speech therapy in 7 Divisional Secretariat divisions in Hambantota district, with the assistance of a network of 150 trained volunteers. In addition to these services are the pre-schools for children with learning disabilities and a prosthetics unit (established recently).

6 BasicNeeds pilot projects are located in the following GN divisions: Thalawa-North, Thalawa-South, Kariyamaditta, Debokkawa and Rathmalwala.

During the consultation process, we were informed of mentally ill people who have never been treated or taken care of. Due to their poverty, families could not afford to take them to the hospitals where mental health services are available. The BasicNeeds Sri Lanka team worked with Dr. Neil Fernando, the former Mental Health Director of Ministry of Health, to develop the community mental health module to suit the needs of mentally ill people and the community. After having discussions with mentally ill people and their family members in their homes during field visits, the structure of the module best suited for the community was designed.

The BasicNeeds project team tested many alternatives to see how people could best gain appropriate consultation and treatment facilities. As a direct result of this initiative, with little adjustments in the policies and practices of service-providing institutions and individuals, the following mental health services are now available in the project area:

- Monthly mental health camps by a multi-disciplinary team of mental health professionals from the National Mental Hospital, Angoda.
- 'Satellite' mental health clinics conducted by the government Medical Officer - Mental Health of the Hambantota District Hospital in the project areas on the second and fourth Fridays of every month.
- Mental health clinics integrated into medical clinics of district hospitals run by medical officers having basic training in mental health, for drug administration.

Village volunteer committee members play a significant role in encouraging mentally ill people to use the services available and monitor progress. The volunteers are trained in the basics on mental health, and have thus gained confidence in serving their own community members. They also lead self-help group activities organized around mentally ill people. Some volunteers have donated small pieces of cultivation land to start group farms. Temples and schools in these villages also play a supportive role by providing infrastructure facilities and getting involved in socializing activities with mentally ill people.

Stigma and discrimination have been tremendously reduced. As one volunteer described: 'The word we earlier used to describe a mentally ill person is no more used in these villages'.

The commitment and hard work of our field volunteers has made it possible for BasicNeeds to co-opt the Southern Province Ministry of Health into our programme on the ground. Medical officers and institutions in the province have already begun making new initiatives to address the needs of people with mental illness. The twice-

'Something significant I noticed during family education programmes is that the mentally ill people and family members volunteered to come out with their problems and discuss them openly with their fellow participants. There was a session where the participants, in particular the mentally ill people, were invited to talk about their experiences with medication and they discussed certain difficulties they faced, including side effects. This open discussion gave us a lot of insight into problems that the patients face, which we were not aware of. It was a learning experience for us.'

Dr. Neil Fernando, Consultant Psychiatrist, Ministry of Health

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Ready to serve:
young volunteers sign up at consultation workshop

weekly clinic that is being run by the GMO of the Thalawa-Kariyamaditta District Hospital is just one example.

BasicNeeds Sri Lanka has also developed a mutually supportive relationship with the Director, Mental Health of the Ministry of Health. This has enabled us to help reflect community needs and interests in the formulation of policy and the setting up of systems.

The BasicNeeds Sri Lanka programme proves that mentally ill people can actively participate in the development process, provided that their basic needs are addressed and basic rights are respected. It started small—inviting mentally ill people, carers and community members to join hands to help each other.

Today, there are about 100 village volunteers working with mentally ill people with much support from professionals in mental health and development. A third of the volunteers are carers of mentally ill people or have been mentally ill themselves. The programme will expand its coverage in southern Sri Lanka in the near future, in partnership with mentally ill people, carers, volunteer committees, and government and non-government sectors.

Destitute mental patients stranded in mental hospitals and rehabilitation centres are also involved in our work, especially in the sector of Horticulture Therapy. About forty patients are involved in this project which is conducted in partnership with the government. The programme plans to extend this pilot project into a commercially viable enterprise by involving at least 60 participants.

‘I feel happy and proud that I am doing something worthwhile. Our duty is to empower people through awareness, building capacity and consultation. That is more than enough for them to stand for their rights. It is not us who got drugs available at their hospital. Despite our efforts, if they had not visited and convinced doctors, even today they would not be able to make drugs available in their locality.’

K. Sunil, Mental Health and Development Coordinator, Navajeevana

Ghana

Programme Manager:
Peter Yaro

Lance Montia handed on the role of Programme Manager to Peter Yaro in March 2004. Lance moves to Accra to continue the good work.

Northern Ghana occupies 30 per cent of the total land area of Ghana—70,373 square kilometres with a population of close to two million. Tamale is the headquarters of the thirteen administrative districts of the region.

The region's level of development contrasts sharply with the rest of the country. Health and sanitation facilities are the barest minimum. For instance, in 1990, it was estimated that there was one doctor for 63,095 people—the national ratio was one doctor for 20,450. There are only four hospitals capable of dealing with emergencies and 119 health clinics that cater for minor illnesses. Most people turn to herbalists and traditional healers for treatment.

Working out practicalities:
Chris on an exploratory visit in Accra

There is no psychiatric hospital and no psychiatric doctor in the whole of the northern region. The region has 11 psychiatric nurses, one on leave in the UK, and the balance 10 distributed among its 13 districts.

BasicNeeds Ghana works in partnership with the Ghana Health Service of the government to address the needs of mentally ill people and their families. Treatment is brought as close as possible to communities through the visits of the Chief Psychiatrist, Dr. J. B. Asare. The supply of drugs is regular and free and medical assessment and follow-up occurs every three months.

Community visits by medical personnel and volunteers have aided early assistance and sensitized people about mental illness. Equally importantly—community-based organizations like the Amasachina Self Help Association, Youth Alive, Mandela Development Centre and the Gubkatimali Society are beginning to involve mentally ill people and their carers in their work. Amaschina has agreed to accept mentally ill people on their credit scheme.

The plight of people who have mental illness is now being made public. BasicNeeds Ghana regularly participates in discussions on local and national radio and television that underscore the need to integrate services for mentally ill people into general health provision. Dr. Asare had this to say when the presenter asked him what precisely he has been looking for:

> "I have been looking for mentally ill people who need treatment, and to standardize the treatment so that the health providers[1] in the areas I visit would continue to follow up— using the same approach."

1 District Health Directorate of the Ghana Health Service

Service provision has always centred on institutions. However, in the case of Northern Ghana, because the three major institutions are in the south of the country, the patient has to travel by bus, under sedation, with his family— a very uncomfortable and sometimes cruel procedure. The BasicNeeds approach has shown that community mental health care was possible and appropriate. The involvement of families helps people achieve both recovery of their health and regaining of a means of livelihood.

Extensive consultation and feedback have meant that capacities have been built at individual, group, and community levels. The process of group dynamics used by BasicNeeds provides people with a sense of belonging and real involvement. Additionally, their participation in the design and review of the programme creates a sense of ownership.

Ti Sampaa means 'Our Meeting Place' in Dagbani, and for mentally ill people in Tamale it means just that—and much more. It offers space for recreation and access to treatment. Ti Sampaa was conceived by BasicNeeds Ghana and the Ghana Health Service.

Ti Sampaa is located right next to the Regional Psychiatric Unit in Tamale. It replaced a dilapidated building used by the psychiatric team in the last 22 years.

Ti Sampaa is a day centre and halfway house that facilitates dialogue with family before people return to their homes and community after institutionalized treatment. It is likely to be a model that would be replicated in other parts of the region and the country.

'After failing my exams I thought that was the end of my world knowing everybody was expecting me to make more outstanding grades. After a while I decided to give up everything and leave things to God. But what could I do after my illness? I was idling at home all the time when fortunately I came into contact with BasicNeeds through Mr. Iddi Adama and Madam Amina Bukari at the Tamale Psychiatric Unit. They invited me to meet Dr. Asare at the Shekhinah Clinic at his outreach visit. I received medication and there is now great improvement in my health. I am determined to develop the potential I have in me. When I get some financial support I will be able to make it in journalism or go to the teacher training college.'

Asmawu Bukari

AHMED ABUKARI (CLIFF)

Learning by listening: consultation meeting on access to mental health services

People depend less on the Accra Psychiatric Hospital, and the Pantang and Ankaful hospitals. More volunteers are being trained.

The Amasachina Self Help Association implements the sustainable livelihoods systems module of the BasicNeeds Mental Health and Development Model. The key aim of this project is to develop systems for the integration of the mentally ill people and their families into mainstream society through the provision of productive capital.

The Gubkatimali Society carries out advocacy and awareness work so that both the general public and the authorities are more aware of mental illness and mental health issues.

Our resource partner the Shekhinah Clinic provides food and medical care for destitute mentally ill people on the streets.

Our programme is currently reaching 2,417 people with mental illness through consultations and outreach services and 2,175 family members and carers.

Our interventions prompted the formulation of a draft Community Mental Health and Development policy by the Ministry of Health. Health care managers and government officials are slowly working towards changing policy. Meanwhile, the application of the BasicNeeds model for mental health and development continues. And most significantly, the Ghana Health Service is building capacity to deliver mental health services at community level.

"I am glad about the BasicNeeds initiative. Patients often relapse after going home and not getting the care and love of their families. There is also lack of funds to buy drugs. Rehabilitation centres for the mentally ill to learn basic skills like masonry and sewing is a good idea. I believe we need community care in Ghana. We have to establish centres in all the districts."

Dr. S.K. Allotey, psychiatrist, Patang Hospital

tanzania

Programme Manager:
Abdallah Magawa

The most fundamental problem that mentally ill people face is the systematic denial of the right to treatment. This is reflected in the state of mental health services in developing countries. Tanzania is no exception.

Formal mental health services in the country are acutely deficient. There is a serious shortage of trained personnel. Institutions like Mirembe and indeed the psychiatric department at Muhimbili National Hospital have limited facilities for mentally ill people and, in most cases, focus mainly on severe psychiatric cases.

Tanzania has 11 practising psychiatrists, based almost entirely in the capital Dar es Salaam, for its 37 million people. The Mtwara region in the south of the country is an area where poor communications and weak economic prospects mean that many people struggle to get by. Apart from the ten-bed ward at the Ligula regional hospital, mental health services in the district hospitals are almost non-existent.

Other factors that have a bearing on people's ability to access treatment include levels of awareness and income and distance to the health facility. There is also hardly any social activism in the field of mental health.

BasicNeeds Tanzania initiated a programme on community mental health and development in the southern Mtwara region. We worked closely with the Ministry of Health to develop the programme. Our work in the five districts of the region emphasizes both access to treatment of mental health and the development of sustainable livelihoods.

Aumizae Ahmad is a woman suffering from a psychosomatic disorder. She has to walk a total of sixteen kilometres from her village called Ziwani to the Ligula Regional Hospital in Mtwara, where she collects her medicine, and back. *'I don't have bus fare, so I walk to and from the hospital in the burning sun once a week for my medication.'*

SHOBA RAJA

Mentally ill people, their families and carers have been placed at the centre of the programme. They have been consulted on their needs and experiences, as a strategy of empowering these groups for self-advocacy including the right to treatment. In a span of just two years, 1,200 mentally ill people will have benefited from our programme.

Despite the fact that mental health is a part of the primary health care policy in Tanzania, it has never being given any attention in local and national-level planning or in the country's Poverty Reduction Strategy. BasicNeeds Tanzania also focuses on raising awareness on the needs of mentally ill people among government officials, policy makers and various groups of people at different levels.

We are capacitating health providers at regional, district, and primary level through a series of training programmes on the basics of mental health and development. We have also begun sharing our approach to mental health with traditional healers.

Dr. Msonde, the district medical officer for Tandahimba, one of the districts in which BasicNeeds works, describes one of our biggest challenges: *'I am authorized to order anti-psychosis drugs from the National Medical Store department, but then, they will end up in the stores and finally burnt because we don't have a specialist for prescribing such drugs.'*

We have planned to facilitate the setting up of ten outreach clinics, two in each district, and drug distribution to health centres.

Breaking news:
BasicNeeds Tanzania launching ceremony

'This programme does not belong to BasicNeeds. It is our programme. BasicNeeds is facilitating the process that we have been charged with. To ensure that this project is successful we need to demonstrate good results. Remember that supporting and facilitating development programmes is part of the election manifesto of the ruling party.'

Regional Commissioner for Mtwara at the BasicNeeds Tanzania Launch, 2003

right to be treated to be treated right

uganda

Programme Manager:
Tina Ntulo

Daniel Iga Mwesigwa, a 43-year-old Ugandan male who has been mentally ill since he was thirteen, puts it this way: 'If I take the medicine I cannot work. If I do not take the medicine I cannot work.' The supply of newer drugs is erratic and the cost expensive—most Ugandan families can't afford to pay for them. Daniel believes the situation creates further dispossession: 'Having the right treatment opens doors to opportunities like education and acquiring skills. Lack of treatment affects my right to education, gainful employment and finally my right to enjoy my life.'

Uganda, with its population of 24.6[1] million, has fifteen psychiatrists and three neuro-surgeons—ten do administrative work, some teach, and the rest work as private consultants. All of them are based in Kampala, the country's capital. But the fact remains that nine out of ten Ugandans live in rural areas and an estimated six per cent of the rural population are mentally ill.

Social stigma associated with mental illness and epilepsy is widely prevalent—people go to hospital for treatment only as a last resort. Most referral hospitals rely on clinical officers and community nurses to treat illnesses they know very little about.

Limited medical knowledge about mental illness extends to health planners. This means they are unable to make informed decisions about mental health services. The health system uses illnesses that cause death as a basis for health planning and budgeting—putting mental illness at the bottom of the list. The mentally ill often have to make do with drugs that are old and outdated. Frequent side effects cause patients to discontinue medication.

Uganda has several NGOs working on the ground with persons with mental illness and epilepsy. One of their gains has been the recent inclusion, in the National Health Policy, of mental health at primary health care level as a follow-up on WHO's recommendations for mental health. Although a lot more lobbying needs to be done to ensure that these gains in policy are implemented at the grassroots, this is indeed a considerable achievement by these organizations.

It is with these groups that BasicNeeds will work. Our key partners are Mental Health Section, Ministry of Health,

1 2002 Census

MARY ANNE COATES

New alliance:
Tina with USDC Team after a planning meeting

Kampala; Butabika, the National Mental Health Referral Hospital, Ministry of Health; Ugandan Society for Disabled Children (USDC, Uganda); Mental Health Uganda (MHU); Epilepsy Support Association (ESA); Kamwokya Christian Caring Community (KCCC); Development Research and Training (DRT); Traditional & Modern Health Practitioners Together against HIV/AIDS & other diseases (THETA).

Dr. Sheila Ndyanabangi, the Mental Health Co-ordinator, Ministry of Health, is working on a Mental Health Act and reviewing curricula for mental health. The Ministry has shown much enthusiasm about the adaptability of the Mental Health and Development model to the Ugandan context.

BasicNeeds Uganda aims to achieve:

The establishment of **partnerships and alliances** that create links between users, policy-makers and service providers.

Changes in social attitudes towards mental illness through strong user groups who will promote integration and reduce stigma.

A **holistic approach to mental health and development** through the testing, adapting and implementing of the BasicNeeds Model. This work will be in line with Uganda's draft Mental Health Policy.

Increased **knowledge and understanding of the situation of mentally ill people** through user-led research and participatory processes, coupled with improved understanding of policy processes, leading to targeted advocacy and awareness-raising activity.

The African Development Bank has pledged to support infrastructural development of six regional mental health units—including infrastructure for a mental health unit with both in-patient and out-patient facilities as well as rehabilitation facilities carried out at this level.

The bank is also expected to fund:

1. Strategy formulation to include mental health services in the minimal basic healthcare package.

2. Training of psychiatrists, psychiatric clinical officers, health officials and nursing assistants.

3. The review of curriculum for health workers to include mental health issues.

policy research

Programme Manager: Shoba Raja

Initial field consultations with mentally ill people and their carers, and interventions in communities reveal that mental illness is widespread in poor communities. The vast majority of people do not have access to treatment. Health conditions worsen, productivity and family incomes decline, and poverty intensifies. Stigma of mental illness operates strongly to further exclude people from their communities.

Professionals in the field of mental health almost universally accept that mental illness is today one of the leading causes of the global burden of disease[1]. Not just that—it affects twice as many poor people as it does the rich[2]. Countries across the world—especially low-income countries—invest less than one per cent of their already meagre health budgets on mental health. This reveals the huge gap between need and policy.

None of the countries in which BasicNeeds works has effective mental health legislation or resource allocations that can even begin to meet the needs of mentally ill people. However, there are attempts in most of these countries to shift to a community-based approach by bringing mental health into the ambit of primary health care.

Mental health policy formulation in developing countries will have to take into account people's poverty and developmental realities including the poor state of health infrastructure. But there is little research evidence of actual practice of mental health policy in these contexts.

Evidence from BasicNeeds' field operations across Asia and Africa clearly illustrate this. The on-going action research of our interventions, in different geographical locations, is beginning to show the kinds of change that is possible. Importantly, people with mental illness, their families and communities are beginning to realize the potential for change through effective interventions, where access to treatment is a first and crucial step:

'I have been mentally ill since childhood. Now, in the recent past I have got 'vimukthi'[3] from my illness.'

1 Murray CJL, Lopez AD. *The global burden of disease*. Vol 1. *A comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990, and projected to 2020*. Cambridge, MA: Harvard University Press, 1996

2 Cross-national surveys in Brazil, Chile, India and Zimbabwe, (Patel et al. 1999) from WHO's World Health report 2001

3 Liberation or freedom

ANIL PATEL

Documenting evidence:
Valli Seshan and Naidu visiting a partner

'Changes have happened among people at home and in the village, because my condition has improved.'

At BasicNeeds, research is embedded in practice. Field programmes work through existing local resources and infrastructure to achieve significant milestones of treatment access, recovery, getting back to work, earning and participating in family and community. Action or 'practice' research[4] provides quantitative and qualitative data of such hands-on experience in various ways. Working in parallel, **Policy Research** consolidates information on mental health and related legislations, policies, resources available, and decision-making processes in the countries we work in and in global forums. A bringing together of the two in analysis[5] leads to information relevant for policy debates, influencing and formulation.

Country programmes demonstrate ways by which people with mental illness gain access to treatment and then go on to develop themselves within their families and communities. Along the way, they generate evidence of this process—from local to national levels—to influence policy.

Our international Policy and Research Programme facilitates the process of policy influencing by setting up research methodology, systems and processes appropriate to each country, training of country teams and developing strategies. The experiences from different countries are encapsulated to bring forth the voices of people with mental illness at a global level. The programme is now beginning to network internationally with other policy partners to develop arguments for cost-effective mental health policy and practice options for developing countries.

The 'voices' of people with mental illness form a significant part of our research evidence base. Analyzing their own situation, their needs, and, importantly, the change in their lives, is empowering. People are able to recognize the significance of different milestones in planned interventions, starting with treatment and recovery. This builds their capacity and enables them to demand their right to treatment and to development.

4 Norquist G.S., Commentary, (Information Needs for Community Practice) Int. J. Mental Health Policy Econ 2, 87- 89 (1999)

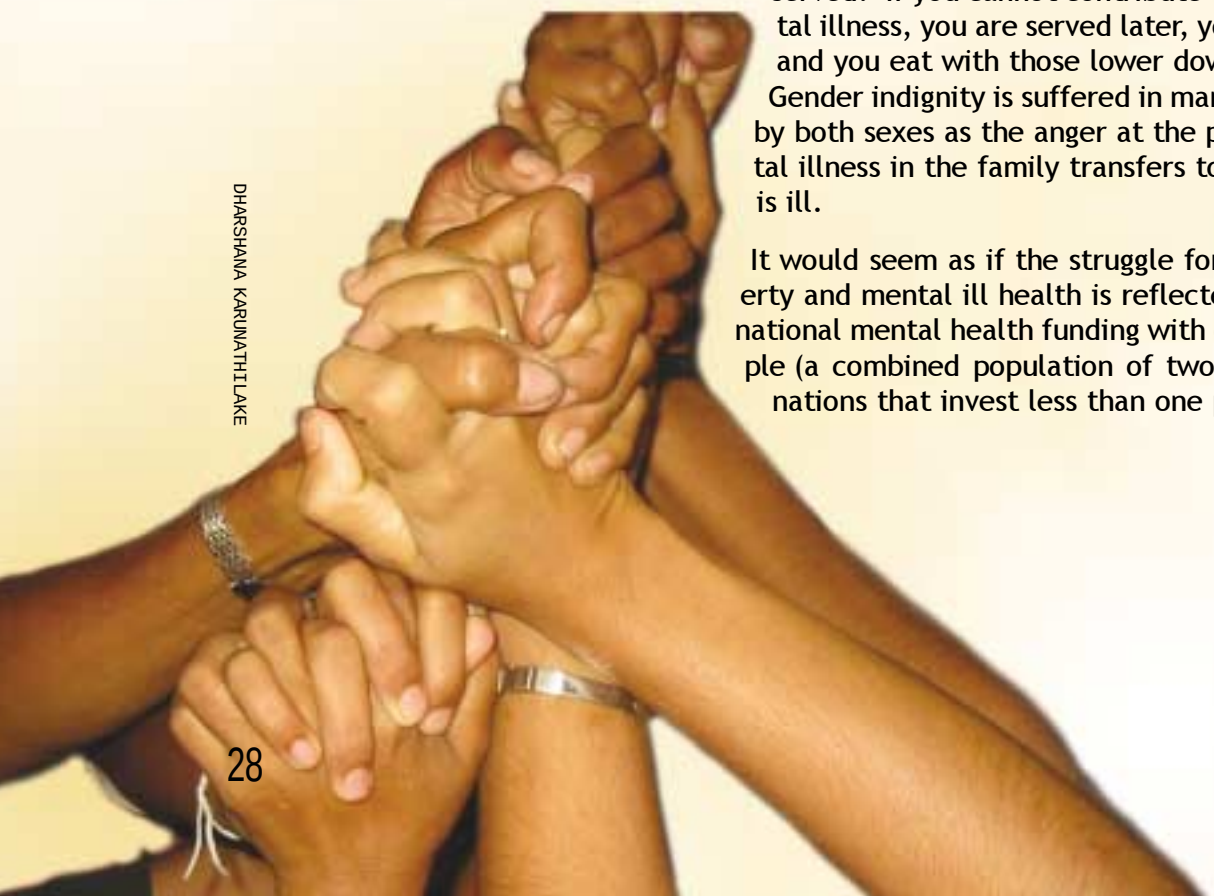
5 An example of this is the discussion paper *Mental Health - the Policy Landscape in India*, presented by BasicNeeds India at a national mental health policy workshop that BNI coordinated with the British Council, February 2004

strength behind us

Individuals and their families in most developing countries find themselves in a very serious resource crunch with the onset of mental illness. The mentally ill person stops earning and so, soon enough, does the person who has been assigned as a carer. The visits to healers, the travel to the city to consult a psychiatrist, the purchase of drugs, all lead to extra pressure on the family budget.

If you are very poor, decisions have to be taken about who eats first from the family meal pot. If you are a man and a labourer you will have eaten with those who were first served. If you cannot contribute due to your mental illness, you are served later, you get less to eat and you eat with those lower down the hierarchy. Gender indignity is suffered in many different ways by both sexes as the anger at the presence of mental illness in the family transfers to the person who is ill.

It would seem as if the struggle for survival in poverty and mental ill health is reflected in the field of national mental health funding with one third of people (a combined population of two billion) living in nations that invest less than one per cent of their



DHARSHANA KARUNATHILAKE

DHARSHANA KARUNATHILAKE

Sense of ownership:
Savudias helps set up livelihoods workshop

total health budget in mental health. It is a sad truth that many developing nations don't know what it would cost to treat their current population of mentally ill citizens.

Some countries see things differently. A total of 127 districts (out of a possible 500) nationwide will be funded at an approximate cost of $440,000 per district for a period of five years by the Indian Government's District Mental Health Programme. Whilst this funding will come from the Indian Treasury, many countries, however, cannot afford to fund more than the national mental hospital from their own resources. The Ugandan Ministry of Health has sought a loan from the African Development Bank to develop mental health units at six regional hospitals. This is a huge commitment demonstrating that a small African economy can adjust funding priorities even when facing population losses due to HIV/AIDS.

Governments lose vital contributions from the workforce through both communicable and non-communicable diseases. In terms of national funding of health provision it makes sense to invest some of the scarce funds in relatively inexpensive mental health treatment. Once treated, many mentally ill people can return to work. Alas this is not the case in the area of communicable diseases where a high level of deaths deny both families and the nation of workforce contribution. Difficult choices of course, but it is increasingly clear that governments cannot simply choose to fund communicable disease treatment at the expense of non-communicable disease treatment.

The above notes are by way of illustrating the setting in which we as an organization work. Additionally, they act

as a backdrop to our own resource generation. How does BasicNeeds find the resources to carry out its programme? This question is often asked of us and we are happy to answer it. BasicNeeds sets out to make a point about mental health in a development context. The governments from the countries where we work provide us with substantial 'in kind' resources, mainly with regard to medical staff. Part of the work of the organization has been to work with aid and development funders so as to establish the case for funding the field of mental health in the developing world. The idea has been to grow the organization so as to lay a pattern of programmes in different settings and countries, permitting us to speak about mental health and development with authority and experience.

I think the main aid and development funders support us because they wish to explore a new area of work, once perceived as welfare or medical, and now proposed as a new initiative in mental health and development. It is also the case that our programmes are set in the wider agendas of these major players. For example, meeting the general community health provision concerns of the Community Fund, the rights-based interests of DFID and the self-advocacy concerns of Comic Relief. Our work meets and contributes to the UN millennium poverty reduction goals. And this is the right place to be for a small powerfully-motivated charity with a new way of looking at an age-old problem.

We are very grateful indeed to our special supporters who continue to support our work from their own resources. The relationship between a special supporter and the gearing up that can be achieved in developing a larger programme is very interesting. Chris Mathias and his family have supported the Indian programme whilst it made the transition from our original core funding to the major grant offered by the Community Fund permitting us to work in the southern states of India with seven major partners. A range of trusts and foundations have also helped with

ANIL PATEL

Standing for mental health rights:
Nick Hewson in India on Mental Health Day

ANIL PATEL

Making time for people:
Nick Hewson at community meeting, India

strategic grants in the same way, enabling us to build longer-term relationships with the bigger institutional funders. The support from the UK-based charity the Health Foundation has been very important for us to establish a programme with our partner NBJK in Bihar and Jharkhand and two training programmes in Tanzania that will prove both testing and challenging. Baring Foundation and the Sylvia Adams Trust have both helped with innovative funding schemes. Finally, we are now welcoming donations to the charity from a larger and larger group of individuals who are literally giving what they can afford to our work 'because it's a good cause' as one donor wrote recently.

We remain ever grateful to our founding donors World in Need who have been very generous indeed with their fi-

Listen!

Support BasicNeeds and receive your copy of 'Listen' the newsletter that keeps you in touch with our new initiatives in mental health and development. Write to the Editor: winifreddalby@aol.com

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Visit our website regularly at

www.basicneeds.org.uk

right to be treated to be treated right

nancial and human resources and to the Joel Joffe Charitable Trust who donated to us in the first years because it was indeed difficult work.

Above all we set out to be practical and to demonstrate what can be done using the model for mental health and development. This pragmatic approach appeals to donors of all kinds. They also appreciate the way in which the work once demonstrated in one place can be transferred to another. Poverty manifests itself in many ways and poor health is both a symptom of poverty and a cause of it. As poor mentally ill people struggle to return to a more stable condition so as to support their families; once again, it is our job, with our funders, to work alongside them in their support. Just as it is for us to work alongside the governments where we work, making the case for better and differently apportioned resource-use in support of better treatment for mentally ill people.

Should you wish to support BasicNeeds, please write to Chris Underhill, Founder Director, at the address below or e-mail:
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For the latest copy of our audited accounts, please apply to Jane Cox, Finance Manager, e-mail:
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ANIL PATEL

View our e-journal at
www.mentalhealthanddevelopment.org

Molecular Products Group plc is one of the world's leading innovators in chemical technologies for the purification of air. Founded in 1924, the business employs seventy-five people on two sites: sixty are based in Thaxted, a small rural town in England, with a further fifteen based near Denver in the USA. The business has very strong values of honesty and respect, and over the years has nurtured a strong identity with its community.

The work done by BasicNeeds in underdeveloped global communities embodies these values and is the reason why Molecular Products is so keen to be associated with BasicNeeds.

'The right to be treated, to be treated right' both summaries and typifies the work carried out by BasicNeeds. With rights comes responsibilities, and in the world community in which we live the responsible behaviour of companies is of paramount importance. Molecular Products is pleased to support the ongoing work of BasicNeeds.

Ian McKernan

Chairman & CEO
Molecular Products Group plc

molecular

D. M. NAIDU

Together we made it:
Valli Seshan (left) and Amelia meeting in India

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right to be treated to be treated right

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DHARSHANA KARUNATHILAKE

Walking and working:
Mike and Magawa with project team of Sri Lanka

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We say Goodbye and warm thanks for your commitment!

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right to be treated to be treated right

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To be heard

is to be recognized.

To be recognized

is to gain hope.

Hope will

make you

free.