



# WORK IN PROGRESS

By

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# A Model in Mental Health and Development:

## Work in Progress

### Introduction

The scale of the global challenge posed by mental illness has become increasingly clear in recent years<sup>1</sup>. Mental illness now accounts for about 12.3% of the global burden of disease<sup>2</sup>, and this will rise to 15% by the year 2020<sup>3</sup>. While this enormous health burden is increasingly being recognised, so too is the inadequacy of our global response.

The World Health Organisation (WHO) recently published the first global profile of mental health services<sup>4</sup> and it clearly shows that mental illness, in most countries of the world, is simply not taken seriously. Forty per cent of countries have no mental health policies and 25% have no legislation in the field of mental health.

As one might expect, 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 1% of their total health budget in mental health<sup>5</sup>. In general, lower income countries invest proportionately less in mental health, and this is especially the case in Africa and South Asia. Community care facilities have yet to be developed in about half of the countries in the African and South Asia Regions.

The availability of mental health professionals in large areas of the world is extremely poor. More than 680 million people, the majority of whom are in Africa and South Asia, have access to less than one psychiatrist per million of population.

### The background evidence

There is persuasive evidence that in the developing world non-communicable diseases such as depression and heart disease are fast replacing communicable diseases as the leading causes of disease burden<sup>6</sup>. Prof. Rachel Jenkins in assessing the mounting awareness of the importance of mental disorder cites<sup>7</sup> three influential collaborative reports:

1. A collaboration between The World Health Organisation (WHO) and the World Bank entitled *Investing in Health* (World Bank 1993) calculating that the global burden of neuro-psychiatric disorders was 8.1% as measured by DALYS – Disability Adjusted Life Years.
2. *World Mental Health*<sup>8</sup> which after presentation to the UN in 1995 resulted in the WHO setting up a major initiative known as “Nations for Mental Health” with the aim of improving mental health in developing countries.
3. *The Global Burden of Disease* being a five year data compilation by the Harvard School of Public Health, the World Bank and WHO.

With respect to this last report Prof. Jenkins goes on to point out that five of the ten leading causes of disability worldwide in 1990 (measured in the number of years patients have had to live with a disability) are psychiatric conditions, namely:

1. Unipolar depression
2. Alcohol abuse
3. Bi-polar affective disorder
4. Schizophrenia
5. Obsessive compulsive disorder.

With regard to future projections she concludes:

*“...the contribution of psychiatric disorder to the global burden of disease in 2020 is expected to be immense. The projections show that psychiatric and neurological conditions could*

*increase their share of the total global burden of disease from 10.5% of the total burden to 15% in 2020. This is a bigger proportionate increase than that for cardiovascular disease.”*

### **Impact on development**

The economic impact of mental ill health is phenomenal as it is on the lives of huge numbers of individuals, their families and communities for by the year 2020 “depression will disable more people than AIDS, heart disease, traffic accidents and wars combined”<sup>9</sup>. In 1999: “...in Europe and the USA alone US\$120 billion were lost in direct costs and productivity losses because of neuro-psychiatric disorders. Depression alone accounts for US\$60 billion.”<sup>10</sup>

The impact on people in developing economies is less quantified<sup>11</sup>. At BasicNeeds, however, we see the reality of very poor families struggling to keep their chins above the flood of poverty that submerges them through mental illness, as first one family member reduces their contribution to daily income flows, often to be closely followed by a second. The reason for this is that the family assigns a second person to care for the first. This may be out of concern but it is also due to pressure from the community repudiating the presence of a mentally ill person wandering in the street without supervision. In turn the carer, apart from reducing their income, often becomes depressed and increasingly dysfunctional.

Mental health is inherently a development issue, not only linked to poverty but also to gender imbalances, education and awareness. It is dictated by both biological and socio-economic constructs. “Gender determines the differential power and control men and women have over the socio-economic determinants of their mental health and lives, their social position, status and treatment in society and their susceptibility and exposure to specific mental health risks” and “Gender-specific risk factors for the common mental disorders that disproportionately affect women include: gender-based violence, socio economic disadvantage, low income and income inequality, low or subordinate social status and rank and unremitting responsibility for the care of others”<sup>12</sup>.

Mental health cannot be viewed in isolation, for it influences, and is influenced by, development, gender, poverty, levels of education and awareness, the provision and implementation of policy and legislation, and issues of access to, and availability of, treatment and care. It follows that mental health is a significant part of the mainstream<sup>13</sup> of health and development activity for any community anywhere.

### **BasicNeeds introduced<sup>14</sup>**

Established in late 1999 and operational by mid-2000 BasicNeeds is a development organisation whose specific vision is that “The basic needs of all mentally ill people, throughout the world, are satisfied and their basic rights are respected” whilst its mission is “To initiate programmes in developing countries, which actively involve mentally ill people and their carers and enable them to satisfy their basic needs and exercise their basic rights. In so doing, stimulate supporting activities by other organisations and influence public opinion”.<sup>15</sup>

BasicNeeds’ own work confirms the findings reported on a larger scale by the WHO and the other commentators mentioned in the introduction above. Indeed through our growing programme experience we particularly note the tremendous limitations in trained personnel and facilities. In Northern Ghana, Lance Montia, Programme Manager, noted in his baseline<sup>16</sup> study that there were 9 retired and 6 practising psychiatrists in Ghana. Our Representative in Tanzania, Mary Ann Coates, reports that Tanzania spends 4.8% of GDP on health but notes that the percentage allocated to mental health is undeclared<sup>17</sup>. There are currently only 11 qualified psychiatrists in Tanzania.

A very striking aspect of global mental health is the extent to which the state is often the only player in the institutional landscape. In countries where the voluntary sector has a proud and plentiful tradition, such as India, with a few notable exceptions the presence of non-governmental organisations (NGO’s) is really quite extraordinarily slight. To take India as an example, acknowledging along with the quoted source that the information is not so much exhaustive as indicative, the total number of NGO’s supporting persons with mental illness amounts to 43 in the whole country. This includes family groups like AMEND and the BasicNeeds India Trust is also in that number.<sup>18</sup> Significantly in talking to mentally ill people

in our current programmes we have found that they were almost never part of community based rehabilitation schemes, development programmes or income generation projects<sup>19</sup>.

### **The work of BasicNeeds**

BasicNeeds works in two states in northern India, four of the five states in southern India, the southern province of Sri Lanka, the northern region of Ghana and, soon, the southern most area of Tanzania, Mtwara Region. Work in Uganda, Kenya and Bangladesh is under plan at present. In addition the organisation runs a number of global programmes notably the Research, Policy and Advocacy programme managed from BasicNeeds India and the Programme Management System<sup>20</sup> operated from BasicNeeds Sri Lanka. The organisation is de-centralised with only four staff working from the UK office.

### **The mental health and development model**

In developing this model, now being developed by all the programmes mentioned above, Chris Underhill (with much support from DM Naidu) has borrowed heavily from other fields (development, group dynamics, income generation, medical extension etc). The WHO has put forward 10 overall recommendations for working with mental illness in the community and the model may be regarded as an attempt to provide a methodology for implementing the recommendations. The model itself is divided into five modules:

1. Capacity building
2. Sustainable Livelihoods
3. Community mental health
4. Research
5. Management and administration

#### **1. Capacity building**

In order to achieve our aim of reaching a substantial number of people we have decided to work through the additional capacity of other people's organisations. These are known as partner organisations and can vary tremendously in scope and overall size. In the capacity building module we support our Community Based Organisation partners so as to equip them to work with mentally ill people. Typically, and for obvious reasons, most of our partners have not worked in the field of mental illness till they join our work. They generally come from such backgrounds as Community Based Rehabilitation and the field of general and economic development. In turn many mentally ill people and their carers (often family members) go on to form their own self-help groups, supported by the relevant partners. Additionally, carers may also form groups both for mutual support and to provide innovative mechanisms of care for mentally ill people. We use a form of group dynamics called *animation* to support all the organisations we work with be they groups of mentally ill people or formal organisational structures.

#### **2. Sustainable livelihoods**

Communities change their opinion of mentally ill people very slowly. If they do it is often because the mentally ill person has begun to earn a little money for the family. Thus a sustainable livelihoods approach is not only an effort to reduce absolute poverty but is also seen as part of the context that might reduce stigma and facilitate reintegration into family, community and society in that order. The programme identifies the capabilities of individuals and helps them either to return to their former employment or supports them to seek out micro enterprise opportunities sponsored by Government or such micro enterprise specialists as the Bridge Foundation in Bangalore.

#### **3. Community Mental Health**

There is no doubt that many people who turn up for the consultative meetings (capacity building) are absorbed by their own sense of being mentally ill or of being affected by the presence of mental illness in others. They want to know what is "wrong" with them and how to put it "right". In one way or the other we have to find methods with our partners to extend diagnostic and other medical facilities to those seeking help. A common form of extending specialist provision, especially in India, is the so-called "camp" system. Information is gathered, arrangements are made, the specialists arrive and "set up camp" in a convenient place, such as a district hospital, and start to see patients for diagnosis on a pre-agreed

basis. The majority are looked after locally and only those that need it are sent up the line to a secondary or tertiary place of care (depending on the levels in the system).

The lives of mentally ill people in northern Ghana has been altered by the presence of both nursing and psychiatric specialists who have been able to diagnose and prescribe for a limited number of people to date. However, the success of this module will depend on other timely interventions as well as the directly medical. For example, the training of CBO staff to act as “bare foot” counsellors, and the training of local general and district based practitioners to supplement more specialised staff will all be important factors in the module’s effectiveness.

#### **4. Research**

The research module is intended to do three things:

1. Acquire empirical data
2. Collect the life stories of mentally ill people, as told by them, concerning the major events in their lives – and the use of these stories to influence local society and the wider community
3. Document the significant processes that occur as people come together for the first time and decide to form groups, etc.

Shoba Raja our Head of Policy based in Bangalore has recently reported on a participative meeting in which the first three of our many Indian partners met to decide on their data collection strategy. The point being that data collection should be useful to both partner and BasicNeeds and, above all, mentally ill people.

As a result of the research we have carried out with mentally ill people, we are now able to contemplate our first serious piece of advocacy work, which will be on the theme of an **equitable access to treatment**.

#### **5. Management and Administration Module**

The Management and Administration Module is of great interest to our Community Based Organisation (CBO) partners, since it offers training in project management, including log frames, budgeting and finance, monitoring and evaluation, and reporting. The partners use these measures for their development but also to fulfil the needs of their agreement with BasicNeeds – all spelt out within a Memorandum of Understanding (MOU). Smaller partners find the basic training valuable in the conduct of their relations with other partners.

### **Work in Progress - Discussion**

Working with mentally ill people in a developmental way has, of itself, been extremely exciting. It has all the possibilities of a “win-win” situation. Generally, mentally ill people want to stay at home<sup>21</sup> and feel tremendously anxious at not being able to make a contribution to domestic income flow and the social activity of the family. Most governments freely admit that they are in no position to cope with the total volume of mentally ill people needing support.

The admission of mentally ill people into hospitals for either short term or long stay treatment is often arbitrary, depending upon the proximity of the patient to the facility in question. Anyway, generally, admission into mental hospital is not a sensible solution. Most of the institutions in the countries we work in are not places that give confidence that they would be either therapeutic or even safe<sup>22</sup>. With regard to the model, only about 15-20% of a mentally ill person’s time is spent in a medical context. After an initial period of treatment the rest of the time is spent in returning to work, re-invigorating social ties and generally getting on with life. That is the point of treatment after all. Whilst no doubt there are many therapeutic characteristics arising within the model overall most of the modules were designed to be developmental rather than therapeutic.

All monitoring and evaluation carried out within the administration and management module is done on a participative basis, with the presence of all stakeholders, including mentally ill people. By way of reviewing work in progress within the model, perhaps it would be useful to

open several “windows” on the Annual Review Meeting of BasicNeeds India Primary Partners?<sup>23</sup>

The texts below, appropriately edited, are directly pasted from the review document.

#### **First window:**

“The first question was from Amali<sup>24</sup>, addressed to SACRED. She wanted clarification on how they were able to say that **social stigma had reduced** through the programme. Yeriswami<sup>25</sup> answered this query. He began saying that he could *only* quote actual examples that showed that stigma had been reduced; examples based on which he and Tipanna<sup>26</sup> had made that statement in their list of significant changes.

*Examples of mentally ill people who have recovered and are stable in their recovery<sup>27</sup>:*

1. Akullapa<sup>28</sup> – earlier people in the village used to call him “mad” They don’t anymore. Akullapa was never invited and he never attended any functions in the village or family. Now he gets invited and attends marriages etc.
2. Chowdappa<sup>29</sup> – *Drought in Anantpur is severe and recurs. Usually there are community rituals offering prayers for rains. This involved carrying pictures in a procession, usually through several nearby villages. This year Chowdappa was **asked** to carry the picture. He had to lead the procession through seven villages. This was in contrast to earlier years when mentally ill people, even physically disabled people were not allowed to take part in the rituals.*
3. Gopallappa<sup>30</sup> – *Earlier people in the village used to throw stones at him. Now he visits people’s homes. People treat him with respect.*
4. Venkatrama Reddy<sup>31</sup> – *Earlier several people used to tell SACRED staff “Why are you dealing with this family. Its no use” Everyone had left them (abandoned the idea that anything could be done for them). But now after seeing the changes they are all talking about it. Not only that if there are jobs available (casual labour) they give first preference to V. Reddy.”*

#### **First window closes**

#### **Second Window:**

The next point discussed was from Natesh. It concerned the listing of “**gave free medicines**” as a significant happening. The discussion, analysing if giving medicines was a good strategy or not, was animated. Opinions varied to include the following:

- ?? “It is significant but significant because it has brought change, the person (illness) has improved.
- ?? ” But is it positive or negative?”
- ?? “ Attitude of people (to medicines) changes if it is given free. If not free then they make it their business to take regularly.”
- ?? “ If free they think it is my (field worker) responsibility. No value for it.”
- ?? “ How long can we continue (afford) to give free medicines”
- ?? “If government give free medicines we must stick to getting that. If we are giving free we should get their participation (contribution).”

Naidu<sup>32</sup> summed up this debate about medicines<sup>32</sup> saying medicines were an issue and we should all ponder about all the above points discussed.”

#### **Second window closes**

#### **Criteria for judging change:**

The involvement of the participant in a programme must be surely be one of the most critical factors of success in beating back chronic poverty. We have established five major criteria by which we will judge the success of our programmes: These are:

1. To impact on the lives of poor women and men and their families
2. Change in policies, practices, ideas and beliefs
3. Changes in gender balance / equity
4. Involvement of people with mental illness problems in the programme
5. The sustainability of change.

As a way of illustrating the application of the change criteria to the model some examples have been taken from a recent progress report prepared by Chintha Munasinghe our Sri Lanka Programme Manager.<sup>33</sup> With regard to the impact on the lives of poor mentally ill women and men and their families Chintha noted that one person who had been completely excluded from the family, due to his behaviour, was recovering fast after medication. He did stop taking alcohol and marijuana and was working in the field. He had been offered a contract to clear a piece of land nearby. Regular referrals were now being made to Dr. Neil Fernando, psychiatrist, and this meant that a number of people were now participating in the programme who had not done so before.

A quote from the same progress report: "The same visit to village was an eye-opener for Dr. Neil Fernando and Mr. K.M. Herath (General Matron). Having "village rounds" instead of "ward rounds", the consultant psychiatrist decided to change his practice by adding a new feather to his hat – Community Based Psychiatry. He agreed to lead the community mental health team of BasicNeeds, providing his expertise for the development of Mental Health model at Primary Health Care level focusing on Southern Province". Neil will lead on adapting the WHO 10 recommendations for implementing a community based programme to our model.

With regard to gender it was noted, in the Sri Lanka work, that the majority of participants at consultation workshops were women and that the majority of caregivers were also women. In some cases it was the husband who was the mentally ill person and therefore the women were also bread-winners.

The sustainability of change at field level revolves very much around the capacitation of the partner. In the case of Sri Lanka the partner is Navajeevana. Sustainability is going to depend upon their ability to take on board a new model in an effective way and integrate the work of the mentally ill people into the rest of their activities. This harmonisation of work is key to the effective partnership.

### **Drawing the threads together**

Whilst no doubt there will always be exceptions, the model is intended to serve a large number of people. At present we have been busy building a programme base and will need to continue to do this for some time to come. This is to give BasicNeeds the financial resources and the credibility we need to promote community models at all levels.

The model is intended to reach a substantial number of people. Thus, by the end of 2003 we intend to work in India with 3490 mentally ill people and approximately 3450 families making a total of 20,700<sup>34</sup> people whilst in Sri Lanka we intend to try and reach about 1000 mentally ill people. In Ghana work began in the Northern Region in April 2002. In 2003 the Programme Manager anticipates working with 560 people suffering from mental illness or 2,800 family members and carers. As our partners and us reach a reasonable volume of people we are going to have to develop further systems for overall management. This is in hand with the appointment of a Chief Operating Officer in the UK (making our fourth UK member of staff) and a well developed Programme Management System working out of Sri Lanka as well as a first class financial system being developed world wide.

Michael Oliver<sup>35</sup> reminds us that whilst the resources of medical specialists may be essential, the boundaries between them and disabled people need to be renegotiated. This is also true in the case of mental illness. However, in a world where the social model of health is not much implemented most of the people we have consulted feel understandably that they lack power – so it is not surprising, even if it is paradoxical, that they might want a powerful health professional to fight their corner and to validate their situation. Supporting all parties to move away from these limiting confines is an important role for any development organisation. Excellent and inspiring examples can be found of this shift being undertaken by many mental health professionals as well as mentally ill people.

If you are very marginalised within your own community inevitably you turn inwards. The hard reality is that most communities expect you, whatever your pain, to make the first step to



solving “your own problem”. A community based programme such as that managed by BasicNeeds and its partners is, clearly, designed to locate you and to then offer some support and some solutions. Yet, to achieve recognition that you are taking care of yourself and in return deserve, within the bounds of local mores, to be less marginalised is not so simple. This negotiation of “you and the community” is bound to be more fluid, to be more problematic. It is about finding a space, within the *body politic*<sup>36</sup> of your community, into which you fit and perhaps can then enlarge with the acts of contribution to family income etc. After that, who knows, your re-entry into the rituals of your society may seem not only possible but a fulfilment of your dearest wish?

Expectations are a strange thing when developing a model of this type. We had expected for the North Ghana programme to make contact with relatively smaller numbers of mentally ill people during initial consultation phases. Instead, in the first four months the team have consulted 355 mentally ill people and 397 caregivers and family members in an epic series of preliminary meetings. Although in the end the North Ghana programme will have a smaller number of mentally ill people to work with than programmes in India, what appears to be universally effective is 1) asking mentally ill people and their families what the issues really are, 2) how a programme can be put together to start them on their own course of development and 3) made it happen! Simple acts of process cannot be under-estimated in importance, significance and empowerment. Most of the people we work with at BasicNeeds are hungry to state their own minds and they do so with force and the absolute lucidity that self-knowledge and poverty bring. The work continues.

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- <sup>1</sup> Desjarlais R, Eisenberg L, Good B, Kleinman A. World mental health. Problems and priorities in low income countries. Oxford: Oxford University Press, 1995
- <sup>2</sup> World Health Organization. World health report 2001. Geneva: WHO, 2001
- <sup>3</sup> 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
- <sup>4</sup> World Health Organization. Atlas: country profiles on mental health resources 2001. Geneva: WHO, 2001
- <sup>5</sup> World Health Organization. Atlas: country profiles on mental health resources 2001. Geneva: WHO, 2001
- <sup>6</sup> Murray CJL, Lopez AD (1996), The global burden of disease, WHO, World Bank and the Harvard School of Public Health, Boston
- <sup>7</sup> Jenkins R, (1997), Nations for mental health, Soc Psychiatry Psychiatr Epidemiol 32: 309-311
- <sup>8</sup> Dejarlais R, Eisenberg L, Good B, Kleinman A (1995), World Mental Health - problems and priorities in low income countries, Oxford University Press: Oxford
- <sup>9</sup> Bill Wilkerson; President of the Global Business and Economic Round-Table on Addiction and Mental Health, Toronto, Canada
- <sup>10</sup> Marten de Vries, Professor of Social Psychiatry and Epidemiology at Maastricht University in the south of the Netherlands current Secretary-General of the World Federation for Mental Health speaking on Radio Nederland, reproduced by their Science Unit in an article by Anne Blair Gould, 24<sup>th</sup> December 2001.
- <sup>11</sup> WHO World Health Report, 2001
- <sup>12</sup> WHO website on mental health
- <sup>13</sup> The disability movement have done much to *mainstream* issues that were formerly regarded as specialist or, indeed, segregated into professional field such as rehabilitation. There is some way to go in the field of mental health.
- <sup>14</sup> Further info at [www.basicneeds.org.uk](http://www.basicneeds.org.uk)
- <sup>15</sup> Underhill C, (2002), BasicNeeds Strategic Plan 2003-2007, Leamington, unpublished
- <sup>16</sup> E-journal *Mental Health and Development* published by BasicNeeds: [www.mentalhealthanddevelopment.org](http://www.mentalhealthanddevelopment.org)
- <sup>17</sup> World Health Organisation Atlas
- <sup>18</sup> NIMHANS, (2001), 'Foundations and Techniques in Psychiatric Rehabilitation – Manual for CBR Workers and Caregivers' NIMHANS, Bangalore
- <sup>19</sup> Chris Underhill in Selected Readings in Community Based Rehabilitation, Asia Pacific Disability Rehabilitation Journal, Series 2, Disability and Rehabilitation Issues in South Asia
- <sup>20</sup> A system of monitoring and evaluation
- <sup>21</sup> Field observations by Chintha Munasinghe, Programme Manager BasicNeeds Sri Lanka, and Dr. Neil Fernando, Consultant Psychiatrist Government of Sri Lanka.
- <sup>22</sup> Murthy, R. S. (2000). Community Mental Health In India. Mental Health In India - 1950-2000: Essays In Honour Of Professor N.N Wig. (Ed) Murthy, R.S (Pubs) People's Action For Mental Health (PAMH), Bangalore.
- <sup>23</sup> BasicNeeds India, (2002), Annual Review Meeting Primary Partners, Bangalore; unpublished
- <sup>24</sup> Partner senior member of staff
- <sup>25</sup> Partner
- <sup>26</sup> Partner
- <sup>27</sup> In all these people diagnosis (was made) and regular treatment started only after interventions through the partnerships
- <sup>28</sup> Akullappa diagnosed as having Schizophrenia for eight years before he began treatment
- <sup>29</sup> Chowdappa, around 32 years of age, diagnosed as having mild mental disability with behavioural problems and whose treatment began only after he came into contact with SACRED.
- <sup>30</sup> Gopallappa diagnosed as having schizophrenia for over eleven years.
- <sup>31</sup> Both Venkatarama Reddy and his father had mental illness (but untreated) for over two years as gathered by SACRED staff. Venkatarama Reddy was severely ill. Also the family was virtually starving, as his mother was the sole earning member doing casual agriculture work. Now the local Panchayat (elected village level self government body) has arranged for regular supply of rice to the family from the government Public distribution system through its 'food for work' scheme.
- <sup>32</sup> Programme Manager BasicNeeds India and one of the architects of the model

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<sup>33</sup> Munasinghe C, (2002), Progress Report of July – December, Colombo; unpublished  
<sup>34</sup> approx 5 people per family

<sup>35</sup> Oliver M, (1995), 'Editorial: Disability, Politics and Health', Critical Public Health, Vol 6, No. 2, p.3

<sup>36</sup> Influence of the following workers acknowledged: Soja E, Hooper B, (1993), 'The Spaces that Difference Makes', in (eds) Michael Keith and Steve Pile, Place and the Politics of Identity, London:Routledge and hooks b, (1990), Yearnings: Race, Gender and Cultural Politics, Boston:South End Press