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DIMENTIONS

A Sochara – Sophea Newsletter November 2013

Editorial

Inter-connected Rights and Multiple Pathways towards Social Justice and Equity in Health

The quest for social justice in health in India is inextricably linked to addressing issues around poverty and development, and in a seemingly contrary way to being humane in all relationships, through a process of constant inner learning, with critical thinking. Within the health sector this search has evolved through praxis, engagement, networking, debate and discourse. A historical and contextual approach that is grounded in research has been one of the paths used. The journey through the Community Health Cell (CHC) and SOCHARA (Society for Community Health Awareness, Research and Action), of working towards the global social goal of Health for All grew through small steps. It began through a response to disaster situations and evolved through networks of solidarity, identifying new pathways as work progressed. Intense interaction with peoples and communities through provision of medical care in the relief camps in West Bengal during the formation of Bangladesh, and subsequently during the Andhra Pradesh cyclone relief and rehabilitation work led some of us to move from curative medicine to community health in the 1970s. Subsequent involvement with the practice of community health for a decade through a medical college seeking to implement its own vision of working with the underprivileged in society provided opportunity for a lot of innovation in undergraduate medical education, and in community based health work, including the training of community health workers in health and development. Through study circles, the Medico Friends Circle (MFC) and an ongoing process of study- action- reflection there developed an understanding of the deeper, underlying societal determinants of health. There was evidence from several health projects in the voluntary sector that the health of people does improve over fairly short periods of time where multiple inputs were made and participatory decision making processes were used. In the 1980s there was an articulation by CHC for the need of a community health movement with a focus on rights and responsibilities. This was an effort to build on work in smaller geographic areas taking it to a larger level. Strengthening of the voluntary health sector and engagement with the state at various levels on health policy issues as part of this process progressed through the 1980s and 1990s, with significant research work in the organization. The urgent need to simultaneously work on the larger national and global health determinants was keenly felt.

The first Indian and Global Peoples' Health Assembly (PHA) held in November-December 2000 in Kolkotta and Savar, Bangladesh respectively brought together a variety of national networks to place health higher on the political and policy agenda and to address the underlying health determinants. The global Peoples' Charter for Health adopted by participants at the PHA, and endorsed later by thousands of people world - wide, continues to be a source of inspiration and a call for action towards equitable and sustainable improvement in health. The Charter states that *"Health is a social, economic and political issue and above all a fundamental human right. Inequality, poverty, exploitation, violence, and injustice are at the root of ill health and deaths of poor and marginalized people"*. It moves on to outline areas for action at multiple levels.

This charter reinforces and expands on analysis, commitments and statements that derive from concepts of justice, fairness and rights in the WHO constitution (1946), the Indian Constitution (1950), the Alma Ata

Declaration (1978), the ICMR and ICSSR report (1981) and many other documents. There have been a number of initiatives to realize the goal of working towards 'Health for All' both preceding and post its clear articulation in the WHO conference in Alma Ata in 1978. These initiatives have been inspired by a number of ideologies and philosophies, including most prominently Gandhian, Marxist, Humanist etc. Historically a number of these strands came together (in response to an international call) around the year 2000 when it was obvious that despite all efforts and some progress,' Health for All' still remained a distant dream.

Building on the 1966 UN Conventions inter-connected rights provide a basis to address the societal determinants of health often called the underlying or distal determinants of health. The Indian Peoples' Health Charter provided a sense of urgency in its call, "*we reaffirm our inalienable right to and demand for comprehensive health care that includes food security; sustainable livelihood options including secure employment opportunities; access to housing drinking water and sanitation; and appropriate medical care for the Right to Health for All, Now!"*

The Indian Council of Social Science Research (ICSSR) and the Indian Council of Medical Research (ICMR) in its 1981 book titled 'Health For All, An Alternative Strategy' stated, "*While adopting the Constitution on 26th January 1950, we the people of India dedicated ourselves to the creation of a new social order based on equality, freedom, justice and the dignity of the individual and to that end, decided to eliminate poverty, ignorance and ill health.'*

The Global People's Health Charter conceptualizes social justice as "*a world in which a healthy life for all is a reality; a world that respects, appreciates and celebrates all life and diversity; a world that enables the flowering of peoples' talents and abilities to enrich each other; a world in which peoples' voices guide the decisions that shape our life".*

Public statements by several thinkers highlight the unacceptable and growing disparities in the living conditions and the health status of the social majority in India. Civil Society Organizations (CSO) have for long been raising similar concerns. WHO and the Health Promotion community in a recent Helsinki Declaration (July, 2013) recognized the role of CSO's and social movements, making a case for closer interactions between the state and CSO's.

Despite significant gains in terms of policy directions in a number of areas, and improvements in health indicators since 2000, social inequities in health and in access to health care remain a serious issue of concern. The environment is becoming more complex with widening health gaps and disparities. The reasons for this are many and have been much discussed and debated.

In the international and national arena too there have been changes, with gradual disappearance of the term 'Health for ALL' and the emergence of the concept of Universal Health Coverage (UHC). In India there has been significant debate on the issue with the medico friend circle (MFC), and later the JSA and other academic groups leading the discussions in the alternative sectors which have influenced in different ways the evolution of national policy process. The expression of policy intent is reflected in documents of the Planning Commission, and more recently by the National Advisory Committee. The relative neglect of attention to the underlying societal determinants of health, and to the basic premises of comprehensive primary health care such as community participation in decision making and an inter-sectoral approach, needs to be discussed and urgently redressed.

In view of the developments mentioned above and the continuing vulnerability of large numbers of persons, families and sections of society in India, who are the social majority, it is a need of the hour for the health movement to respond adequately and with a sense of urgency.

"Social Justice in Health: Research, Advocacy, Training and Action on Realizing Health Rights" is an initiative that builds on the history of the Community Health Cell from 1984, and of SOCHARA from 1991. It aspires to strengthen efforts towards realizing the global social goal of 'Health for All' (HFA) first articulated in the Alma Ata Conference of 1978. The goal of freedom, development and health was intrinsic to the Freedom Struggle of India and other movements and efforts. Hence a historical and contextual approach is being adopted in this initiative which has a research, documentation and communication/ dissemination dimension.

SOCHARA as part of its commitment of supporting the health movement has embarked on a process of critical reflection of the movement in an effort to distill from our collective experiences lessons that we may take forward in our quest for social justice in health. The group is reflecting on multiple pathways that contribute to the realization of inter-connected rights that lead towards the HFA goal.

Using the move towards Universal Health Coverage as a point of departure, we felt that rather than discussing the

minute details of a possible model of Universal Health Coverage – developed by the MFC and subsequently by the *Jan Swasthya Abhiyan* and other groups, the aim is to address the question *"what have we as a health movement and as a community of health workers and professionals learnt from the activities, campaigns and initiatives in the past that will inform our actions and health work including health policy to progress more equitably and effectively in the future?"*

A subsequent publication from this initiative, covering these areas more comprehensively will be ready shortly.

We would like to record with appreciation the work done by Ms. Lavanya Devadas in bringing this Newsletter together. She was a member of the Social Justice in Health team and brought to us a sensitivity and creativity in all our publications during that period as well as in her work. Our warm thanks to all the contributors to the Newsletter!

Thelma Narayan, ***SJ Chander, Rakhal Gaitonde***
SOCHARA

The Rights of Persons with Disability – Need for Judicial Accountability

– C. Mahesh

The role of the Executive in implementing the various laws pertaining to the Rights of Persons with Disabilities and Role of the Judiciary – with regard to non-implementation of the various laws pertaining to Rights of persons with disabilities, needs to be explored carefully.

Before I start, I would like to share my story which is now 20 years old. I am from Bangalore and I was doing my 2nd year B.Sc. degree during which time I contracted a viral fever that left me with weak limbs. I dropped out of college as my house was on the first floor. I could not walk up to the bus stand or make use of the college bus and the classes in my college were in different floors.

I wanted to get out of my house, study, earn, hang-out with friends but there was no place to go – I could not use the public transport, go to a hotel/ temple/ wedding hall/ cinema house as there were steps and there were no toilets which I could use.

Over the years, I have come to terms, accepted my disability and I know how to handle my disability. I do not mind if you call me as a person with disability or challenged or differently abled, the bottom line is - very little has changed in our society and in the environment around us.

One could argue that things are much better now, than it was some years ago. But that is no reason for us to be complacent. The Bangalore City Corporation has amended their bye-laws to ensure that public buildings/ external environment should have provisions such as ramps, signage and toilets so that persons with disabilities can have equal access. Can we at least think of redesigning the 'Nimala Bangalore - Pay and Use' public toilets in the city to ensure persons with disabilities are able to make use of this facility like everyone else? Can we have pavements that all pedestrians can use safely and independently?

There has been no dearth of policies and documents in India. In recent times, in October 2007, India has been among the first few counties in the United Nations to ratify the Convention on the Rights of Persons with Disabilities (UNCRPD). Numerous Government orders have been passed to address the various concerns in ensuring and protecting the rights of persons with disabilities.

The greatest challenge continues to be in the way, we as people and society understand disability and the needs of Persons with Disability.

Our society - parents, teachers, politicians, bureaucrats, shop keepers, bus conductors continue to respond to our need in a way that they are doing us a favour. What we need is to access the services in a way that is sensitive to our needs and in a way that dignifies and acknowledges our existence.

Disability is a social issue, which demands a socio-political response.

Existing laws for persons with disabilities

We have a wonderful Constitution meant to protect each one of us. It is as meaningful to you as it means to me. Just as you can, we too have the same right to express ourselves; I too have the same opportunity just like everyone else. But I never knew that I had these rights; I did not know that I could ask my college to provide me with a ramp to attend the computer classes that was located in the basement.

I was not aware that the isolation that I was facing is violating my fundamental right – Article 19 – Right to Freedom – Imagine, if you are traveling in a train for more than 12 hours and you are the only one who is unable to use the toilet. Is this not a violation of your Right to Freedom? This is what we experience.

Article 21: ***Right to life and personal liberty*** – everyone has the right to live life of a certain minimum standard, but we readily accept it when persons with disability are almost permanently imprisoned in their homes or in institutions for life.

Before the enactment of the different Special Laws such as the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act (PWD Act), 1995, The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999, Mental Health Act, 1987, the responses to addressing the issues of persons with disabilities were very feeble. With the enactment of these special laws, the activism in the field of disability is becoming more strong and visible.

The recent policies and programmes such as the "*Sarva Siksha Abhiyan*" - Education for All, has made provisions for including children with disabilities in school and this is an example of how the provisions under these Special Laws are being translated into action.

But are children with disabilities really included in schools? Do they receive education that is sensitive to their needs and abilities? How many private schools are ready to admit children with disabilities? Do children with disabilities get equal opportunities? How many of our colleges care to provide an environment for persons with disabilities to learn? Is this not in violation of the fundamental Right to Education?

The recent deliberations in drafting and lobbying for the ratification of the "International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities" have helped us to understand disability in a wider context under the framework of Human Rights.

However, all these developments have not made any real difference in the lives of the millions of persons with disabilities in our society and in our country.

The role of the Executive in implementing the various laws pertaining to the Rights of persons with disabilities and Role of the Judiciary needs to come under further scrutiny.

Attitudes

The policies and programmes for persons with disabilities based on the principles of 'Human Rights' needs to be understood better by the executives.

Some of the common expressions/reactions are - when the fan stopped functioning in this hall due to power failure, someone commented that "The fan has also become disabled", "When we are finding it difficult to get a job, you are asking jobs for persons with disabilities?" This implies that disabled persons are useless/ dysfunctional.

The education and employment for the hearing impaired continues to be a distant dream.

Children and women with disabilities are most often left behind at home and conditioned to abstain from participating in social events and gatherings.

Discrimination/ violence against women with disabilities are usually taken for granted and never challenged.

Disabled people often run the risk of being infantilized. People who are disabled are more often considered to be asexual. Therefore there is a total denial of their sexual needs or there are efforts made to control and manage the so called 'inappropriate' behavior by them.

All these experiences makes one wonder "Do persons with disabilities have and enjoy the same human rights like everyone else?"

What is needed is a sea change in attitudes towards disability. Where the focus needs to be on the person's ability and our willingness to change our attitudes and adapt the system that respects a person's dignity and one that is more inclusive.

Mainstreaming Disability in Development

The needs of persons with disabilities are perceived as special and are therefore left out by mainstream development programmes.

The Government of India passed the National Rural Employment Guarantee Act (NERGA) in September 2005. This Act gives legal guarantee of a hundred days of wage employment in a financial year to adult members of rural household. The Act would go a long way in checking rural migration and ensuring livelihoods to people in rural areas.

However, according to Chapter VI, Section 40, of the Persons with Disabilities Act, three per cent of all poverty alleviation schemes should be for persons with disabilities. Unfortunately, the Employment Guarantee Act does not make any such explicit allocation for persons with disability.

According to a recent report by the Union Rural Development Minister, Karnataka has generated 35.35 lakh man-days of employment under this scheme. Have persons with disabilities missed the boat again?

It has to be mandatory and ensure that 3% funds should be earmarked for disabled people's employment. People with hearing impairment can do manual work and people with disabilities could play administrative or supervisory roles, or audit the schemes.

In addition, this scheme could be creatively used in the creation of Barrier Free Assets in every village such as - ramps in schools, bus stand, hospitals etc.

Planning, implementing and monitoring programmes

The needs of persons with disabilities should be included in the plans. The Chief Planning Officers in every district should be made aware of the existence of persons with disabilities; hand books need to be provided on ways of including and ensuring persons with disabilities are being included and benefited.

Just as we have 'Fire Officers' certifying buildings, persons with disabilities could be trained and employed as 'Access Officers' who would certify whether buildings and public spaces are in compliance of the barrier-free specifications as mentioned in the building bye-laws of the Bangalore Mahanagara Palike (Bangalore City Corporation), Part IV, Schedule XI, Bye-law No: 31.0 on 'Facilities for Physically Handicapped persons'

All these can happen only if persons with disabilities and disabled people's organizations are recognized and encouraged to participate in decision making bodies.

Employment Opportunities

Persons with disabilities overcome numerous challenges in life, at school and college before they apply for jobs. After all these we are told that jobs reserved for persons with disabilities are no longer there.

Despite Karnataka's stipulation of 5 per cent job reservations to the disabled through its orders in 1995, 2002 and 2005, the Education Department's method of reserving posts for the disabled during recruitment for primary school teachers has actually reduced that figure. Based on a petition, the High Court had also ordered the Government to conduct a special recruitment drive to fill the shortfall. Despite the orders, the Education Department followed the old method while issuing notifications to recruit 7,895 Assistant Teachers for government primary schools in July 2007.

Vacancies reserved for the disabled have not been filled by various departments. The Department of Personnel and Training recently, has asked all Government departments to ensure that posts reserved for the disabled must be filled by persons with disabilities only and if not the reservation needs to be carried forward for the next two years.

The Judiciary should create the precedence in ensuring that persons with disabilities are employed in its courts and ensure that the courts are disabled friendly.

Addressing the loop holes in the Act

The Special Acts do not mention time frames and deadlines to implement the provisions under the Act. Secondly, important sections of the Act are preceded by the clause which says that appropriate Governments shall provide the provisions only if it is 'within the limits of their economic capacity'.

Although the Disabilities Act is excellent, most often the Executive gives excuses or takes shelter in this clause in denying rights to persons with disability.

I cannot pay my land tax and I have to depend on someone as the counter is on the first floor and inaccessible. The Government should introduce temporary measures such as counters on the ground floor till such time a permanent solution is derived. The Government authorities cannot get away by saying 'I have not noticed anyone with a disability trying to pay his/ her tax'. What if the 'authority' himself/ herself experiences a temporary or a permanent disability? Will they have to lead an isolated life till they are 'cured' or 'become normal'?

Creating awareness about the Act

Members of the Judiciary and Executive have to educate persons with disabilities and their guardians about their legal rights, provide hand-outs and conduct workshops. This would also make the persons with disabilities and their families feel respected and wanted in society.

Similarly, the Government training institutes and the in-service training programmes should cover topics related to disability and discrimination and evolve strategies for inclusion.

Efficient Watchdogs

The Office of the Disability Commissioner is responsible for the implementation of the Act. We need to develop a more efficient watchdog mechanism at the state, district and taluk levels.

The functioning of the District level committees and State coordination and executive committees needs to be monitored. The Act specifies that meetings of these bodies must be convened and it also stipulates the time period within which the meetings must be convened. But these meetings are not convened as per the Act.

Training of persons with disabilities and recognizing disabled people's groups as part of the watchdog team would be an effective strategy.

We need to develop trained mediators in the Justice department who would take up the issues of discrimination faced by persons with disabilities.

In Conclusion

The Indian Constitution is built on the foundation of Justice, Liberty and Equality.

There is an urgent need to address the issues of discrimination faced by persons with disabilities in day-to-day life.

"**Nothing about us without us"** - Encourage, support and build the capacities of disabled people's groups and they are ready to be involved in this process of change.

Given the resources we have, and with the right initiative we can make a positive difference in the lives of persons with disabilities and if we have the will to do **nothing is impossible**!

C. Mahesh worked for CBR Forum, Bangalore as the Advocacy Coordinator in promoting the rights of persons with disabilities through 87 of their community based rehabilitation programmes across the country. In addition he was actively involved with the Office of the Commissioner (Disabilities) Karnataka and other networks in creating awareness on the issues affecting the lives of persons with disabilities and advocating for the effective implementation of The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act. He is currently working in the UK.

A Relook at Tuberculosis

– Dr. Gopal Dabde

Tuberculosis (TB) is a major public health problem in India, accounting for one-fifth of the global TB cases. Each year nearly 2 million people in India develop TB, of which around 0.87 million are infectious cases. It is estimated that annually around 3,30,000 Indians die due to TB. Currently, TB kills more people in India than any other country. India has an estimated 40 per cent of the world's cases, killing approximately one person every minute.

It strikes deep at the very economy of the family and the country as well. Having taken note of this in 1962, the National Tuberculosis Programme (NTP) was launched by the government of India with great fanfare and enthusiasm. But 49 years after the launch, with the TB programme having undergone several changes, in name and content, there do not seem to any signs of abating. On the contrary fresh problems seem to be cropping up.

For instance TB has been compounded with the problem of HIV/AIDS, and in addition the major setback because of drug resistance has also become a cause for concern. With all these previous experiences one wonders if it is necessary to take a re-look at this major public health problem. For that we need to look into the nature and history of the disease and also as to how it was almost eradicated in several developed countries. What is that magic wand that made TB disappear or reduce substantially from these countries, while we in India continue to struggle with it? Does our strategy itself need a relook and some redesign?

It was on March 24, 1882, that Robert Koch discovered the tiny germ that causes deadly disease and named it Mycobacterium tuberculosis. He thus revolutionised the scientific understanding of the disease. He received the Nobel Prize in 1905 for this discovery.

Koch did not believe that bovine (cattle) and human tuberculosis were similar but later it was proved that tuberculosis can spread from animals and that too cattle.

The understanding of this particular point seems to have been a major cornerstone, among other factors for substantial reduction of tuberculosis in developed countries especially the United Kingdom and other European nations. These countries selectively identified and isolated cattle that harboured the TB germ. This detection of TB bacteria in animals was done by a simple test known as Mantoux test (also called Tuberculin Sensitivity Test, Pirquet test, or PPD test for Purified Protein Derivative).

It is a diagnostic tool for tuberculosis and if the animal is positive then it is totally isolated (kept around 2 km away from human life) or sent to the abattoir. During its isolation there is a separate staff and exclusive set of instruments that take care of all these animals, until they die a natural death and then are buried away.

Century-old findings

The Royal Commission on Tuberculosis (1907) established

the common identity of the disease in man and cattle under the British Ministry of Agriculture and Food. Under the direction of this Commission in 1929, over 15,000 cattle were slaughtered under the Tuberculosis Order. So it is obvious that it was done on a massive scale and followed up systematically every year until TB ceased to be a major public health problem. The same history of TB control can be observed from other European countries as well.

WHO recognised way back in a seminar titled 'Advances in the control of zoonoses' (http://whqlibdoc.who.int/monograph/WHO_MONO_19.pdf) that it conducted in the year November 1952 that prevention and eradication of zoonoses in human beings can be accomplished in large part by control of these diseases in animals, so that it is natural for public-health officials to give every assistance – moral, financial and scientific to agricultural authorities in carrying out animal-disease-control programmes.

Recent literature in 1998 by WHO reaffirms that in humans the vast majority of cases of tuberculosis are caused by Mycobacterium tuberculosis. However, TB can be caused by Mycobacterium bovis, the so-called 'bovine tuberculosis' which is one of the more prevalent forms and has the widest host range of all TB bacteria.

Knowing the close relation of animals to humans in our villages, more scientific studies need to be done to look at the possibility of the spread of bovine TB to human in the Indian context. While slaughter of cows and other animals are big political issues in India, the government seems to have totally missed the bus on this issue of zoonotic transmission of TB and its prevention.

While political parties and leaders seem to be pumping more drugs to treat TB, we seem to be totally oblivious to the fact that TB disease that is rampant in cows and other animals can also be an important source of the spread of the disease to humans. One wonders if there are other compulsions to look away from the facts just as the ostrich does.

Additional information can be accessed at:
http://www.mediafire.com/?cqx1gr7l716y7

Ensuring Equitable Access in Public Health System

– C. Mahesh

Persons with disabilities are present in every community. They are in all age groups. They are among the rich and the poor, among men and women and among all castes. In India according to the 2001 Census:

- Persons with disabilities constitute 2.13% of the population
- 42% are women and 58% are men
- 75% of the persons with disabilities live in rural areas

However, the figures quoted by the Census are very low because many persons with disabilities were either not counted or the families did not report their presence. The figures are low when compared to other countries in the Asia Pacific Region where Bangladesh reports 5.6%, Sri Lanka 7% and China 6.3%. This in itself is an indicator of how society has rendered persons with disabilities invisible. Therefore the Planning Commission has recommended that even at a conservative level it can be assumed that the percentage of persons with disabilities is around 5 to 6%.

Apart from the fundamental rights that the Indian Constitution grants to every citizen of the country, The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) (PWD) Act, 1995 lists various duties of the government to protect the rights of persons with disabilities such as:

- 'Prevention and Early Detection of Disabilities'
- 'Affirmative Action' like providing assistive devices, access to social security benefits and
- 'Non-discrimination' – in accessing services that are available for all its citizens

In addition, India signed and ratified the UN Convention on Rights of persons with Disabilities (UNCRPD) in 2007 wherein India is obligated to take concrete steps towards ensuring that persons with disabilities get opportunities for growth and development that are guaranteed to all its citizens

However in reality persons with disabilities, either intentionally or due to oversight have often been excluded all aspects of health care. These testimonies of exclusions/ discriminations faced by persons with disabilities are classified as **Human Rights violations**:

1. Persons with disabilities and their families are missing from 'general sensitization/ awareness programs'.

2. Children who are developmentally delayed are frequently excluded from ICDS (*Anganwadi*/ Pre-School) programs.

3. Women and adolescent girls with disabilities are completely invisible in the RCH (Reproductive and Child Health) programs

4. When drinking water facilities are being created in the village / slum, there is no consideration of whether or not these facilities are accessible to people with disabilities .

5. In most instances the toilets are designed in a manner that they are inaccessible to many disabled people (both public and at home)

6. Most PHCs are ***not accessible*** to persons with disabilities, meaning persons with disabilities are not in position to access these services freely, independently and without restriction

7. Despite these challenges, when persons with disabilities do access services in PHCs for common health care issues such as fever or diarrhea they are often referred out.

So what can be done?

- Increase sensitivity of communities and health care providers towards the inclusion and participation of persons with disabilities in their programmes.
- Cultivate the capacity of health care providers and communities to cater to the needs of persons with disabilities such as facilitating access to medical/ disability certificates, ensure that primary health care services address the needs of persons with disabilities
- In addition to a caste, class and gender lens, use the disability lens as well to examine whether health interventions /programs are inclusive of persons with disabilities.

Here is a list of actions you can undertake in your own community to show your solidarity with people with disabilities:

- Ensure inclusion and meaningful participation of persons with disabilities in all decision making bodies.
- Get *anganwadis* and schools to actively enroll and ensure the participation of children with disability.
- Lobby to ensure persons with mental illness have access to medicines at the local PHCs
- Lobby to ensure supplies such as catheters and other incontinence products are available for persons with disabilities and others who need them for a lifetime.
- Ensure PHCs, public drinking water and toilet facilities are accessible to people with disabilities – by constructing ramps, ensuring that the door-width are a minimum 900mm, handrails, and other such support structures.
- Ensure that communication and information on health and related services are available in accessible/ appropriate forms for persons with sensory disabilities such as visual, hearing impairments.
- Ensure persons with disabilities and their issues are included in all health rights campaigns.
- Find out where and how persons with disabilities can access appropriate assistive devices, health care and other related support services – for example appropriate health care services for persons with spinal injuries.
- Enable persons with disabilities find suitable employment opportunities and ensure they access 3% of all development funds.

ENVIRONMENT AND OUR WORLD

Made in Bangalore

– Pushpanath Krishnamurthy

As someone who grew up in Bangalore, I have seen my city undergo a startling transformation, from the Pensioners Paradise to the Silicon Valley of India. I am almost a pensioner myself now – I started writing this blog on my 60th birthday. Sometimes I feel stupefied and amazed by the changes – but I can't feel old: not with so much energy all around me. And from what I see, I feel truly optimistic about the new India, and in particular, the remarkable ways in which a new generation of entrepreneurs is harnessing business skills to tackling the miseries and injustices of the old India.

I have been involved in a study with the Centre for Social Markets into the new forms of innovation pouring out of enterprises here, which we have published as "Made in Bangalore" (www.csmworld.org).

Take Vindhya-Infomedia Pvt Ltd, an IT company that does business process outsourcing. Vindhya employs more than 230 physically challenged young men and

women – two-thirds of the staff. At the door I am greeted by Srinath – I was about to extend my hand to him when I realised he had just two stubs for hands. Seeing my confusion he smiled and explained: "I lost them while working on a construction site. The metal pole I was carrying got stuck to a high-tension wire and my hands were completely burnt. I cannot work on computers, but I can do many other tasks".

Vindhya was founded by 26-year old Pasvithra Ashok and her husband Ashok Gil. Early on they faced many hurdles: for several months in 2006-7 staff had to go without salaries, employees were accommodated in spare rooms and Pavithra cooked the food. Realising the difficulties, the employees said: "Give us one meal, that will do". Now Vindhya has clients ranging from Yahoo to local microfinance institutions and a growth rate of 80% per annum.

Or take Dr Sudhakar Varnasi. He observed that it is possible to deliver a pizza within 20 minutes – yet it was almost impossible to deliver health care in emergencies. Out of anger at that incongruity, Sudhakar created the GVK-Emergency Management and Research Initiative and, in conjunction with the government, now provides the 108 toll free number for emergency services. 108 was the brainchild of Mahindra Satyam who began it in Karnataka. In five years 108 was in 10 states, the only professional service of its kind in India, handling medical, fire and police emergencies. Karnataka's 108 now has 517 ambulances typically able to get to any emergency within 20 minutes – the equivalent of a pizza delivery. In a typical day it saves over 300 lives, and some 8,000 babies have been born in its ambulances. The GVK-EMRI works on a public-private partnership model, with the state underwriting 95% of the cost and GVK and private donations meeting the remainder.

Dr Sudhakar says: "We need to marry the passion and professionalism of the private sector and the power and reach of the government to have a win-win solution. The time is ripe: politicians have recognised that good development is good politics. If the private sector shows the way by transparent, innovative approaches to solve some of these tough problems, partnership with the government can result in phenomenal success, scale and impact".

Let me give one final example. In 2001 the Supreme Court ruled that state governments must introduce a cooked meal at mid-day in all government primary schools. Now Akshaya Patra provides nutritionally balanced and hygienic mid-day meals to 1.3 million children from the world's largest centrally managed kitchen, using cutting edge culinary technology. It is another public-private partnership. The government supports some of the running costs, individuals and corporates like Infosys, Biocon and Bosch provide the rest.

What lessons do I draw from these and many other case studies in our report?

I would say that we are seeing a new stream of business developing and leading the way in taking on the challenges of equity, accessibility and sustainability. These businesses are of many different types; there is no one model. But what they have in common is two-fold: their focus, to tackle poverty and exclusion, and their use of IT to deliver accountability, transparency and – most vitally – efficient and prompt delivery. A new ecosystem of support facilities has started to emerge around these enterprises and what these entrepreneurs are doing has started to be celebrated. A virtuous circle has begun.

So as we all embark on a new year, I see my city changed beyond belief but I feel buoyed by the efforts of these new change makers, not downcast.

Pushpanath is fondly called as 'Push', is Global Executive Social Business & Markets with Oxfam, United Kingdom. Push has spent much of his professional career at Oxfam, where he acquired legendary status for his pioneering work on campaigns such as Make Trade Fair, the Climate Change Hearings, HIV/ AIDS, etc. An accomplished communicator and storyteller, Push takes complex issues and popularizes them for grassroots constituencies using a blend of traditional advocacy and new approaches. Push brings grassroots experience from regions as diverse as East Asia, Southern Africa, the Balkans and the Caucasus, and India. He is skilled in building multi-racial, cross-cultural teams and motivating highly diverse communities. With a background in development studies and agricultural science, Push also brings expertise in issues ranging from anti-poverty programmes, refugee rehabilitation, sustainable livelihoods, agricultural finance; disaster preparedness; participatory development; environmental assessment and gender.

Confluence of Reproductive Health Needs and Climate Change Impacts

– Adithya Pradyumna

While working on my MSc thesis on 'Modelling the health and environmental benefits of meeting unmet family planning need in Uttar Pradesh', in September 2011, I came across several startling facts and figures regarding reproductive health in India, and also about the estimated current and future impacts of climate change on health in India. My project first looked at the maternal and infant mortality figures with respect to the unmet need for contraception. Unmet need, defined as the non-use of contraceptive services among married women who respond to have completed their families, was found to be high in all Indian states through the National Family Health Survey commissioned by the Indian Government. Women who did not wish to become pregnant were finding themselves at risk of it. These unintended pregnancies have occurred in the millions each year, each of which lead to one of the following significant consequences: termination by abortion, delivery of a child, or maternal death.

This phenomenon of unintended pregnancies, though seen in all sections of society including among those using contraception, is mainly seen among the poorer sections. It was also clear from the evidence that most women, though aware about contraceptive services were not using it despite feeling to need for it, and didn't even know that abortion is legal in India. This lack of awareness, along with poor delivery of reproductive health services by the government has resulted in a large majority of women resorting to unsafe abortions conducted at illegal centres by untrained persons for which the risk of mortality is more than a 100 times higher than safely conducted procedures. This, along with poor antenatal and postnatal care has led to maternal death rates almost 100 times higher than that in developed countries, a very shameful situation for a country claiming to be a world superpower. Poor spacing between pregnancies also stem from similar lack of access to family planning services, which also increases the risk of death among the children and the mother. The burden of disease and disability is far larger, by almost 16 times, than the number of deaths. There is an obvious gap between felt need and usage of contraception.

The second part of the calculation looked at the net increase in population due to unwanted births (resulting from a proportion of the unintended pregnancies), and estimated the greenhouse gas emissions due to the consequently increased population, a topic central to the heated debate on the cause of climate change. The figure obtained was found to be relative small, despite the quite large impact on population size because of the relatively small the per capita emission for this section of the population. Interestingly and in parallel to this debate, available evidence also suggests that increased family size adversely affects the family's ability to adapt to impacts of climate change, making them more vulnerable to its effects. This is due to increased poverty and decreased nutrition for each member. So with respect to climate change, improved reproductive health services while seemingly only marginally benefiting mitigation (reducing/halting climate change), but would significantly affect adaptation capacity for those families, clearly very important from a health services and an equity perspective.

From the arguments above, it becomes clearly important for those working in public health to realize the importance of quality reproductive health care for the point of view of health of women and children due to unintended pregnancies, and of the environmental health of poorer sections of the community. There is a need and there is a demand, and it is time that the specific nature of these needs and demands be identified and approached in a thoughtful manner. Justice from a social and an environmental perspective calls for culturally appropriate planning and investment in reproductive health services as per the demands of those who need it the most.

THE TALKING TREE

A Waste Dump: Impacting Health and Livelihood

– Adithya Pradyumna

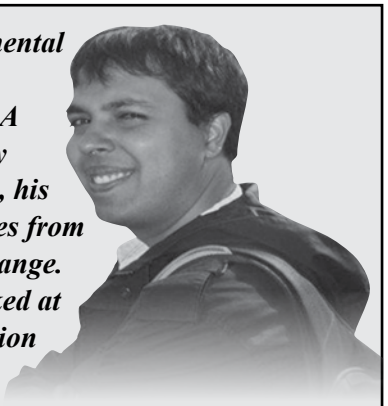
I recently had the opportunity of facilitating a session on basic environmental health research and survey methods for a group of enthusiastic community volunteers. The issue they were facing was a tough one, the largest garbage dump in all of Chennai city, which received almost 3000 tonnes of the city's municipal waste every day. This mountainous dump is located at Kodungaiyur, an area near the coastal edge of the city. The area itself is inhabited by 300,000 people, of whom a 100,000 are in close proximity (or 'exposed') to the dump. Most of the local inhabitants have protested this unmanaged and unhealthy dumping, and have repeatedly claimed that their health and quality of life has been seriously affected. They mainly blame the burning of the mixed garbage which creates smoke and stench which has made life very difficult in Kodungaiyur.

The municipality has decided to turn a deaf ear to these pleas, there being no visible effort for improving the situation despite persistent campaigning over the last twenty years. They community has complained of recurrent upper respiratory infections, asthma and allergies, especially among children. No health study has been conducted in the area, but air samples taken a few years ago showed highly elevated levels of several carcinogens and other pollutants. In fact, a visit to this area or even a few pictures would suggest that there is a serious threat to health. But the continued inaction on the government's part has led the volunteers to look for alternative way to address the situation.

On the other side, apart from having created a nuisance for a large section of Kodungaiyur, the almost three decade old garbage dump has also created an assured livelihood opportunity for many rag pickers. Many of them live around the dump now, and feel threatened when campaigns are held against the dump. The health volunteers are well aware of this.

Thus, the section of the community complaining about the ill health and the section worried about their livelihood have their valid concerns. In the midst of this, the community health volunteers have an important role to play. An attempt to support the community struggle for environmental health justice is very much required to reduce toxic exposure, and it could be done in a way that the rag-pickers community continues to have an occupation in the waste sector, a less hazardous one even. Besides the existing evidence of violation of laws and norms of the garbage dumping at Kodungaiyur, the community volunteers hope to build evidence of ill health and pollution to bring to the attention of the National Green Tribunal of the Supreme Court. The volunteers here become agents of social justice. The important questions being –Is it right for the residents of Kodungaiyur to suffer from the waste generated by the entire city? Is it necessary that garbage be dumped this way at all? And, is it necessary for the rag-pickers to spend ten hours a day in the open heaps of garbage to make their livelihood?

It is unfortunate that such a struggle is needed in the first place. Such neglect of duty on the part of the municipality, though common in Indian cities is not something that empowered communities will stand for. It should not be accepted as the norm for waste management. While there is a role for health research in this, the presence of an empowered community is vital for any degree of success in such struggles. Community health volunteers create a bridge between health evidence gathering efforts and the empowerment of the community, and their work could be greatly supported by appropriate inputs from health organizations with requisite technical skills.



Adithya is an Environmental Health Researcher working with SOCHARA in Bangalore. Relatively young in the profession, his interest in the field varies from sanitation to climate change. Having previously worked at a basic level with pollution impacted communities and occupational health, he now hopes to use his recent training in public health to address a wider range of environmental health problems through evidence generation and application.

In Conversation with PUSH

Take us through some of your personal journey and what inspired you to become a campaigner for the earth?

I was a working child, but managed to go to school somehow. Mostly with the help from many generous people. I will be eternally grateful to the help I received. There are few random memories that made an impact in my life - I went on to work in Syndicate bank that gave me a great learning and implementing development project opportunities. I worked with the villagers of Madanapally, especially with the dalit workers who taught me how to transplant and live within a very small income.

My mother cooked food so we could all eat and survive by selling the same. An international organization like Oxfam trusted in me and placed full confidence in me, assigned many key jobs across the world that taught me so many incredible things about struggle, hope and possibilities. My family-Uma my partner, Shyam and Ahir our sons, who have all somehow managed my madness

I have worked in many parts of the world. My very first learning in campaigning and influencing came about as I advocated for land access to landless in Bijapur. The very first and interesting campaign done in Karnataka by

FEVORD-those days in the 80s gave me a lot of insight and learning.

In Zambia, I worked on a right to information kind of popular campaign during the drought but also connected it to the Zambian Debt campaign mobilizing letters and sending them to Washington for debt cancellation. In Zimbabwe our work on ***Paying for Health: who pays who benefits*** created such a stir that the GOZ wanted to close Oxfam.

In Vietnam I was honored to work on urban poverty and child poverty. In the Balkans each country I worked had an issue in campaigning. But the global campaign called **Make Trade Fair** was the first global campaigning that I did as a full time campaigner for Oxfam GB. We mobilized more than 20 million petitions across the world through many popular approaches.

The impact of climate on the poor led to my full time role as a climate campaigner. I was instrumental in conceptualizing an idea called HEARING about climate. This brought out the horrendous story of the front line impact on very poor women across the world. I trained village women to come and give testimony in PAN AFRICA hearings, Common Wealth hearings and also in Copenhagen. The sad story of impact moved me very much- when I heard the personal stories of suffering. The impact of the stories narrated above prompted me to go on a walk in my personal capacity in 2009 from Oxford to Copenhagen. Similarly, when I went to Malnad in Karnataka and realized that all the work on trade that had helped the farmers over the years has been washed away by 5 years of climatic impact. I decided to walk again from Bababudan to Mysore meeting over 30000 people directly and lakhs through radio. I consider myself the luckiest person to have had the opportunity and privilege of working among many countries across continents.

I am a regular guy with irregular hair –who is fortunate to have had great opportunities to be part of many struggles for real social, economical and political justice across the world! My world view and my life and my family's life are shaped by these intense and personal encounters.

Plight of Farmers and the impact of climate change

It has been said that farmers will be affected by climate change. Considering the marginal existence of most farming families in India, where do you think the situation will head over the next few decades?

I could think of two immediately: impact on coffee growers on the biodiversity of the area; and impact of climate change on farmers. Coffee is the second most traded commodity in the world after oil. This surprising fact confirms the drink's status as the world's favorite beverage. What is less well known is that coffee has been grown and drunk in India for almost four hundred years. Now the beverage is undergoing a renaissance. There are over one million acres under plantation in India, providing employment for over a million workers. The domestic market is experiencing rapid year-on-year growth, and urban India has embraced coffee chains and café culture.

Indian coffee is different. It is special because it is shade-grown. This means it is grown in the shade of forest canopies, sharing space with other plants, vegetation and wildlife. This is not monoculture growing, this is coffee grown in harmony with nature. Indian coffee has many pluses. It contributes to biodiversity conservation, protects watersheds, generates rural livelihoods and soaks up greenhouse gas emissions.

If we can show and demonstrate that a sustainable coffee ecology is good for everyone, for now and for the future that would be a great breakthrough.

Secondly:

Climatic variance as we have seen, hits the most vulnerable and the poorest. Women are the most hit. It hits them first, worst and hardest. Every drought sets back the family by a decade. The unpredictability and the intensity of climate change hurts the vulnerable small holders who are all paying a heavy price already for something that they are least responsible. The accumulated impact is literally suicidal. It is going to get worse. India's longest sea cost, its mountains and its dry areas are all susceptible –we can reduce the impact by providing technology and resources for the people to adapt. Most importantly the international community including India must act- to mitigate and bring down the rising heat. Or else there will be more catastrophes and the poorest will pay the heaviest.

In comparison with farmers and farming in developed countries, how do you think those from India will be affected?

State support towards adaptation is critical. The example of coffee is illustrative: if the smallest holders who are the majority continue to face what they have in the last five years: excess and untimely rain; unexpected dry spells; massive insect and fungal attacks; unprecedented gale- the

vulnerable farmer-will resort to destroy what is the most important and fragile ecosystem. There is more to it. The recent Oxfam Campaign on Hunger says the following-which from experience I know so well as I have worked and travelled in so many countries, ***"Climate change is like the last coffin nail driven unjustly at the very heart of some of weakest and already vulnerable people."***

Today's crisis in the farming community and in rural areas is a grotesque global injustice. Nearly one billion people face hunger every day, while the unsustainable patterns of consumption and production from which they are excluded have placed us all on a collision course with our planet's ecological limits.

The warning signs are clear. We have entered an age of crisis: food price spikes and oil price hikes; scrambles for land and water; creeping, insidious climate change. The 2008 spike in food prices pushed some 100 million people into poverty. Price rises so far in 2011 have done the same to 44 million more. These statistics mask millions of individual stories of suffering and heartbreak as families struggle to cope with deepening poverty. Households falling into debt. Mothers going without meals and healthcare. Elderly people abandoned. Hunger is the bellwether of a deeper malaise. Despite huge increases in productivity and incomes over recent decades, global hunger is on the rise. Despite an overwhelming scientific consensus on climate change and a robust economic basis for swift and decisive action, we continue pumping out more and more greenhouse gases. Despite advances in women's rights and widespread acknowledgement of their key role in ensuring that families eat, women are routinely denied resources, their talents and leadership disallowed.

Governments have neglected the needs of poor and vulnerable populations, especially those of women, demonstrating an alarming lack of will to address the drivers of hunger, inequality and ecological collapse. We now risk a wholesale reversal in human development.

The governments' top priority must be to tackle hunger and reduce vulnerability. They must build resilience by creating jobs, adapting to climate change, investing in disaster risk reduction, and extending social protection.

We must manage trade to manage risk by building a system of food reserves; increasing transparency in commodities markets; setting rules on export restrictions; and finally putting an end to trade-distorting agricultural subsidies. Financial speculation must be regulated, and support dismantled for bio-fuels that displace food. A new global climate fund to finance adaptation in developing countries must be established and funded.

Primary producers in developing countries are also being affected by globalization. In what way could we ensure that global trade considers climate change related equity aspects? Is it possible at all that these aspects will be considered?

The scale of the challenge is unprecedented, but so is the prize: a sustainable future in which everyone has enough to eat. Reaching the new prosperity in time will take all the energy, ingenuity and political will that humankind can muster. To build new governance institutions, invest in smallholder agriculture and reduce global greenhouse gas emissions, we must first overcome the vested interests that have paralyzed the political process until now.

The new prosperity will have to be built simultaneously from the top down and from the bottom up. From the top, ambitious leaders will drive success. Political leaders will resist special interests, inspire their citizens and mobilize support across government to regulate, correct, protect and invest in the interests of the many. Corporate leaders will break ranks with damaging industry lobbies, strengthening the will of politicians and governments genuinely committed to change. They will embrace progressive regulation rather than seek to undermine it or water it down. They will cease to impose their social and environmental costs on others and will flourish by finding ways to make the most of scarce resources, responding to consumer demands and public pressure. From the bottom, networks of citizens, consumers, producers, communities, social movements and civil society organizations will demand change from governments and companies – shifting political and business incentives through the decisions they take and the choices they make. Whether through leading low carbon lifestyles, buying Fair Trade goods, or demanding change in the streets or through the ballot box

The Indian Government has not been able to adequately support the grossly poor majority of Indian farmers, but there are programmes like the Mahatma Gandhi National Rural Employment Guarantee Scheme which may be considered as preliminary attempts. How better can farmers be supported by the government to ensure appreciable adaptation to the effects climate change?

The vast imbalance in public investment in agriculture must be righted, redirecting the billions now being ploughed into unsustainable industrial farming in rich

countries towards meeting the needs of small-scale food producers in developing countries. For that is where the major gains in productivity, sustainable intensification, poverty reduction, and resilience can be achieved. Donor and international organizations must continue to raise spending on agriculture within overall development assistance and invest in agricultural adaptation. New global regulations are needed to govern investment in land to ensure it delivers social and environmental returns.

National governments must provide public support for small-scale sustainable agriculture, while carefully regulating private investment in land and water to ensure secure access for women and men living in poverty. Companies too must embrace the opportunities offered by smallholder agriculture: to diversify and secure supply; to meet growing demand from consumers concerned with sustainable development; to develop new technologies. And active states must intervene where companies fear to tread: to direct R&D towards the right technologies for poor women and men producers; to help them sell their produce on decent terms; to support them with training; and to provide access to finance.

Personal Quest

You have been a campaigner for climate change. Take us through some of the most testing events that you have witnessed as a campaigner through these years.

It broke my heart when I met the so called Grannies of Ginja. There was dozens of them in a small group on a chilly day in eastern Uganda. These brave women at this age should have let their hair down and enjoyed life, but together they were taking care of more than hundred children –mostly orphans left behind by the death of parents due to AIDS and other causes. As I was about to talk to them they all shouted in unison-"we are hungry. we do not have any energy to talk". I was in tears. I rushed to get them some buns and a drink. At that moment I felt that the little crop of maize they were growing was wilting because of prolonged and unprecedented dry period. A problem for which the root cause of global warming was beyond them. It felt to me that the cruelest and a twisted irony of our times that some of the poorest and most vulnerable women are punished further for a problem to which they have not contributed in anyway. That moment, I decided I will walk to tell such stories across the world. And thus I walked to tell a tale in Europe in 2009.

But I always feel Hopeful-even between love and hope I will choose hope if forced to make a choice.

I have never felt more hopeful about India where we can all be winners – we have the resource, the brain power and a youthful population which aspires for a just world. We can and must do it. It is the responsibility of this generation not to fail. The unmet aspiration of the excluded can have catastrophic impact on the whole society otherwise.

Our Tomorrow

What is the vision you have of the world, and more specifically what are your thoughts about our tomorrow when we look at the predicament of our choking earth?

I received a note from Patrick Lameck from Tanzania who said his mother , a maize farmer, can no longer make a living from growing maize because the yield has decreased so much as a result of poor rains that seems to get worse each year. The people in her village are trying out all kinds of new farming practices to survive. They are damming up gullies to create reservoirs, planting crops in trenches that conserve moisture and digging out the moist fertile soil in dry river beds to replace topsoil dried out by the sun. All of the creativity and hard work is not solving the problem. "*It is for these people you are walking my dear friend. We are walking right beside you*."

I carry these feelings, ideas and a sense of possibilities in my minds heart. However, I want to say that just a cog I am, but I still feel I can be always a part of larger struggle for justice and fairness. We are on the threshold of great opportunity to completely re write the very system that we have created but time is running out. ***We must act NOW.*** It is the poorest and most vulnerable people living in poverty who are paying the highest price-with life itself. This must change and I hope, as always, that this is possible, feasible and a MUST.

Mental Health and Development in Community Based Rehabilitation

– The Late DM Naidu

"*The road ahead is long. It is littered with myths, secrecy and shame. Rare is the family that will be free from an encounter with mental disorders or will not need assistance and care over a difficult period. Yet, we feign ignorance or actively ignore this fact*."

Dr. Gro Harlem Brundtland, Former Director-General, WHO

Community Based Rehabilitation (CBR) in India, is very much an issue of basic rights and is opposed to charity or noble work undertaken by any scheme or any group of people.

CBR in India:

It is since 1981, the International Year of the Disabled, that the concept of CBR has been growing in India. It has been largely due to International NGOs (INGOs)and due to the Persons With Disability (PWD) Act coming into existence in India. At least one Ministry i.e. Rural Development appreciated the provisions of the Act and made it mandatory for 3% of its resource allocations to go to people with disabilities in rural India. Small NGOs and Community Based Organisations (CBOs) started addressing the needs of people with disabilities in India. The institutions located in urban areas started functioning as training and resource centers supporting those involved in CBR. Some INGOs who believed in advocacy started self-help groups of people with disability in the villages. Certainly some people with disabilities and their families have been experiencing the change for the good. Here and there one hears the voices of disabled demanding their rights. The flip side of the coin is it's prevalence. In a vast country like India, the question of the number of people with disability from rural areas accessing these facilities and exercising their rights, and their percentage out of the total rural disabled population is unanswerable. *CBR is yet to find an answer to those having severe and profound disabilities.* These services are still delivered by NGOs who depend on external funding sources. *The experiences of those who exhaust resources and do not succeed in making the community self-sufficient to address the needs of this particular cross section of the community never get debated in the right forums.*

When it comes to government programmes/ schemes, one finds the huge gap between policies and realities in the field on one hand and institutionalized corruption on the other hand. In addition, the attitude of service deliverers and people with disability, of course with few exceptions, is coming in the way of real growth and development of the disabled community in a barrier (of all sorts) free environment. Therefore, there is a long way to go and the current pace is very inadequate/ inappropriate. People with disabilities and their families have to clamor for their rights, and certainly as responsible citizens. *The one and only indicator for the success of CBR is people with disability leading dignified lives as active contributors in a community instead of being passive receivers.*

CBR and Mental Illness

Invariably, those involved in CBR work claim that they work with all categories of people with disabilities. They are also quite aware of the Persons with Disability Act, 1995 – Chapter one, section/clause 2 (i) specifies the type of disability covered under the Act. Mental illness is one among the seven. Except a very few that could be counted on one's finger tips in the entire country, none of the projects in India have included people with mental illness in their programmes. Very rightly NGOs have been blaming the government for non-implementation of the Act, while ironically they themselves have not understood the spirit of the Act and do not practice it. From this it is evident both the government and NGOs operate in comfort zones in the name of marginalized groups undermining the very priorities of such groups. It is high time for those involved in any development work in general and CBR work in particular to include people with mental illness in their programmes.

Mental Illness

It is said that one per cent of the population suffer from major mental illness and up to 15 per cent of the population suffer from minor mental illness. This gives us a fair view of the problem that exists in India. 10 million people (7-8 million from rural areas) in India and their families suffer from this chronic illness which is a major stressor for any family. In rural areas the consequences of such illness is a economic and social burden. Extreme poverty exacerbates mental illness and also makes it much harder for individuals to manage their own recovery and the illness itself. This particular group is the most

marginalized one and always has additional suffering due to the stigma attached to it. In rural areas people call any person with mental illness 'mad' or 'mental' meaning gone case. They are socially excluded and are victims of abuse of sorts and human rights violation.

The recent incident in the Errawada asylum in Ramanathapuram district of Tamil Nadu is enough to illustrate the state of affairs of mentally ill people in India. It raises 'n' number of questions including the deep slumber, indifference and sickness of the society. In rural areas people access quacks, faith healers, mantrawadis, etc. Often mentally ill people are subjected to physical abuse, restriction on food, and what not.

These disorders are preventable, treatable and manageable if provided with information, awareness, and required resources including human. There are psychiatric hospitals, centers, institutions, halfway homes, etc., all located in urban areas. NIMHANS has been attempting to give meaning to community mental health. This path is yet to break the ground as required. Resources are very scarce from the point of professionals. It is believed that there is one professional for every 40,000 people. Trained people are not even enough to meet urban needs; who thinks of psychiatric problems in a village?

Why is it a development issue?

Since the community mental health movement has emerged out of a complex interaction among national policies, concepts of human rights, and social needs, it is likely to remain the focus of future developments in service delivery. People with mental illness, like their counterparts, have a right to treatment, employment and to manage her/his life. The law of the land says mentally ill people have limitations as far as the right to property, entering into contract, etc., as they do not have a sound sense of judgment to exercise their rights. However, if a psychiatrist certifies that particular person is having lucid moments, then that person can enter into contracts. Therefore, it is her/his right to lead an honorable life and it is the responsibility of any civil society to ensure such rights being restored.

Development is not an event, or celebration; it is a humanizing process of working with human beings, their emotions, strengths, belief systems, bridging gaps, fighting injustice, etc. Strong belief in every individual's potential is the corner stone for development work.

Local action of global importance

A small group, sensitive to the needs of people with mental illness from the poorer strata, decided to work in this area and named the group as 'BasicNeeds India' (BNI). It is an extremely young organization. The belief is that community based psychosocial interventions would lead to healthy families and community development. Any success in this direction would definitely contribute to poverty alleviation is yet another conviction. The approach is involving people with mental illness and caregivers right from the beginning and working through local NGOs/CBOs – matching needs of mentally ill people, caregivers and people, working with them with resources.

Practical experience with a few groups both in Karnataka and Andhra Pradesh suggests that mentally ill people will only take their place in the development process, as does any marginalized group, by finding ways of achieving knowledge, leadership and resources through self-help and by creating appropriate alliances with other groups in society.

The consultative process slowly evolved into a five-module programme:

1. Capacity building

This will be the basic module that will facilitate the training of CBO partners, which will work with mentally ill people to form their own self-help groups. Additionally, carers may well wish to form groups both for mutual development of various community institutions that can be provided or formed through a capacity building mechanism.

2. Income generation

If the community were to change its notion of mental illness, and its concept of the identity of the mentally ill person within the community's gates, then it might well be through "turning a rupee" – making a little money for the family. Here the programme identifies the capabilities of individuals and those around them who want to be associated with the project and equally the identification of suitable trades within the community that can be merged into micro enterprise. Training the CBOs in micro finance management will be important, as will the links with micro enterprise specialists.

3. Community mental health

There is no doubt that many people turning up for the consultative meetings were absorbed by their own sense of being mentally ill or of being affected by the presence of mental illness in others. It informed the construction and understanding of their own sense of identity. If one is very marginalized within one's own community inevitably he turns inwards to solve "his problem". You may indeed have

an illness which is susceptible to competent intervention, and any rational person would take the prescription would they not? Yet, to achieve recognition that you are taking care of yourself and in return may be less marginalized is not so simple. The negotiation with your own community is bound to more fluid, to be more problematic. In a world where the social model of health is not much discussed, most of the people felt that a powerful health professional in their corner would be of immense help, thank you very much!

A common form of extending specialist provision into any rural area 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 success of this module will depend on other timely interventions as well as direct medical intervention. For example the training of CBO staff to act as 'bare foot' counselors, and the training of local general and district based practitioners to supplement more specialized staff will all be important factors in the module's effectiveness.

In a sense each of the modules on offer are a "place to start" and this module offers the chance to meet a mental health professional and to take it from there. Michael Oliver reminds us that whilst the resources of medical specialists may be essential, the boundaries do need to be renegotiated for most disabled people. In the case of mentally ill and their family members, it needs to be negotiated from scratch.

4. Research

This is a three part module containing as it does an empirical section allowing for the simple enumeration of information – how may people involved, levels of poverty etc. Being attracted to the notion of placing the voice of the mentally ill person at the center of narrative, a series of life stories as told will be developed. These will contribute to the collective body of knowledge and will be published with consent at appropriate times.

Finally a research paradigm known as User Led Research supporting mentally ill people to manage their own inquiry will also be developed. Routine meetings have been process documented.

All of this takes time and effort, and yet the documenting of how such work takes place and its contents is felt to be necessary in a field where, generally, mentally ill people are not involved in community based rehabilitation or in development programmes.

5. Administration

This module will be of great interest to CBO partners since it is through this device that training in project management is offered. This will include training in finance, project management, monitoring, evaluation and reporting.

Conclusion

Prof. Rachel Jenkins in assessing the mounting awareness of the importance of mental disorder cites:

...the contribution of psychiatric disorders 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% to 15% in 2020. This is a bigger proportionate increase than that for cardiovascular disease.

On the other hand in one of consultative meetings with a group of mentally ill people, Smt…… said, "*Nobody loves me; there is nobody in my world*.

You proceed with the exercise and I am not participating".

These two messages are loud and clear and are enough for those involved both in development and health areas to experiment with multi-sectoral approaches, e.g. CBR work, integration with primary health care, income generation and self help group development. Sensitivity, concern and commitment to people with mental illness would ensure their involvement in the development process.

Mr. D.M. Naidu worked tirelessly for persons with disability and mental illness, until his death on the 15th of March 2011.

He was the founder Director of Basic Needs India (BNI) Bangalore. www.prajadwani.org

At a time when mental health was synonymous with psychiatrists and mental hospitals, psychiatric drugs and the pervasive stigma, BNI was a philosophy and an approach that was ahead of its times.

The inspiration and ground level strategies came from the empowerment approach of community development, which was tested on the ground through pilot programs ably by Naiduji and the BNI team for whom he was an inspirational leader.

We remember Naiduji for his immeasurable contribution made in the field of community mental health in India and for being a wonderful friend and human being. We pay tribute to his life by publishing this article he wrote for BNI

A Sustainable Approach to the Promotion of Environmental Sanitation through a SOCHARA Initiative

– I.M. PRAHALAD

Individual health and hygiene is largely dependent on the adequate availability of drinking water and sanitation. Therefore there is a direct link between access to water, sanitation and health. Consumption of unsafe drinking water, improper disposal of human excreta, lack of personal and food hygiene are the major causes of many diseases. Through a SOCHARA initiative to improve the sanitation situation in rural areas of Karnataka several activities have been conducted. Some of these are described later.

Right to Sanitation

Water and sanitation are essential for living a healthy life with dignity. The Right to water and sanitation is essential for other human rights including the Right to life, Right to food, Right to employment and Human dignity.

The Supreme Court has ruled that both **water and sanitation** are part of the Constitutional right to life (Article 21). The Court has stated that *'the right to access to **clean drinking water** is fundamental to life and there is a duty on the state under Article 21 to provide clean drinking water to its citizens'* A.P. Pollution Control Board II v Prof. M.V. Naidu and Others (Civil Appeal Nos. 368-373 of 1999).

In March 2008, the UN Human Rights Council expressed deep concern ***"that over one billion people lack access to safe drinking water and that 2.6 billion lack access to safe sanitation. Access to safe drinking water and sanitation is central to living a life in dignity and the realization of Human rights.***

"Access to safe water is a fundamental human need and therefore a basic human right"-
Kofi Annan, United Nations Secretary general

WHO Definition on Environmental Sanitation – "The control of all those factors in man's physical environment which exercise or may exercise a deleterious effect on his physical development, health and survival."

Training on Community Led Total Sanitation Method

IM Prahalad a young team member in SOCHARA, Bangalore is passionate about promoting sanitation. He works with partners and communities in serveral districts of Karanataka and teaches community health fellows in Bangalore and Bhopal.

Activities under sanitation

The training through **"Community Led Total Sanitation"** method is a process of facilitating participatory exercises using different methods, where local community members realize the adverse effects of open defecation and decide to stop these practice it through collective analysis of their own situation through a triggering process. Various methods were used for triggering this process of understanding and action on sanitation with the community.

Methods used

- **Rapport building** with community members to make them feel comfortable and gain their confidence.
- The **"faeces calculation"** tool especially when it immediately followed the Defecation Map was found very revealing. The members of the community were able to appreciate the level of faecal contamination in their living areas due to open defecation.

- The **defecation area transect walk** (Walk of Shame) is a 'must use tool' since it succeeds in invoking the desired effect with the community.
- **Water and Shit** :- Initially when sealed water in a glass is offered to the community to drink they won't hesitate to drink. But after sometime when we pluck hair and touch it on shit, dip in the drinking water and offer the community to drink, people refuse, and they won't even touch it. Then we explain how drinking water and food is contaminated by shit, how the flies carry shit and contaminate our food and water. This drinking water exercise greatly contributed to the triggering process in the communities.



- The **cost of illness** and health expenditure due to poor sanitation was also one of the triggering tools used to motivate households to build toilets.

materials. During the training 2-3 low cost toilet models were constructed using local masons from the community.


Completed toilets – Appropriate technological option for sanitation

After the triggering process and training of masons the toilets for the individuals were constructed using easily acceptable (low cost toilet model and location specific) and affordable (economic status) toilet technologies and designs. Based on the socio-economic status of the community different models of toilets were constructed by the community costing Rs.900/- to Rs.15000/- INR.

Sanitation through fellowship

SOCHARA Bangalore since several years (2003) has been conducting a "Community Health Fellowship programme" in Bangalore as well as in Madhya Pradesh. The fellowship has a diverse group of fellows from researchers, activists, community builders, community and public health professionals. Water, sanitation and waste management is one of the important topics covered during the fellowship programme using different modules. The subjects covered under sanitation are as follows:




A Case Study of Successful Triggering:

Ramesh (name changed) is a person affected with poliomyelitis. When asked about his defecation practices before triggering he said "I can't walk. My two brothers or any two persons have to carry me to the field for defecation. If no one is present I have to defecate in front of my home. This is very shameful and disgusting."

When staff from SOCHARA - CHC and HeadStreams approached them and motivated them to build toilet at home, the family agreed instantly and on the very same day they arranged for the materials and the toilet was built in no time.

After the toilet construction the family members said "We are very happy that we have our own toilet. Now everyone can use it anytime. Ramesh can anytime use the toilet with minimal help. A wonderful thing has happened to us today because of CHC and HeadStreams. We are very happy and thankful."

Source :- "Sanitation Activities at a village under SOCHARA working area"- Dr. Mohammed Manzoor Akheel, Intern SOCHARA

Training of Masons

Mason training at Raichur, Kolar and Bagalkot district by SOCHARA

Masons play a predominant role in the dissemination of right technical inputs at the village level. In this background it has been felt necessary to orient the masons after Community Led Total Sanitation training methods about different models of toilets in different soil conditions & also to enhance the capacities of the masons during the construction of low cost models using locally available

1. History of Sanitation in India
2. SOCHARA experience in sanitation
3. "Community led total Sanitation" approach
4. Technical guidance on construction of low cost toilet models
5. Eco-sanitation
6. Solid and liquid waste management
7. Appropriate technologies in environmental sanitation

Community Health Library and Information Center

SOCHARA's Community Health Library and Information Center (CLIC) evolved gradually in response to the priorities and emerging issues impacting community health. CLIC has a section on Water and Sanitation where users can access a range of reading materials on various aspects of environment health and sanitation. CLIC also produces Health Digest and Health Round up.

Research in Environmental Sanitation and Community Health

Photo documentation on improper disposal of fecal matter – From SOCHARA

A small research study is planned from SOCHARA on sanitation practices at Yeshwanthpur railway station of Bangalore district, Karnataka state. The objective is to undertake a study on **"Existing sanitation practices at Yeshwanthpur railway station in the context of enhancing sustainability, eco-sensibility and environmental health".**

Resource Mobilization for Environmental Health and Sanitation

No	Activity	Resource Support
1	Unit Facilitation for Environmental Sanitation – core SOCHARA team members working on environmental health and sanitation	Support from KZE, Misereor, Germany
2	Partners at village/ block/district and state level	Network of 6 alumni in Karnataka from the community health fellowship program of SOCHARA who are linked to other NGO's; Government *Panchayati Raj* system; and volunteers from the community.
3	Support for training programs at local level (Training of Trainers - ToT; community led training; training of local masons; and follow up trainings)	Community based organizations who host the training program in the field; Panchayati raj institutions.
4	Support for construction of toilets (financial support)	Own funding by beneficiaries with financial support from a Government of India project titled "***Nirmal Bharath Abhiyan***".
5	Leadership at district/ local level and local facilitators	Resource groups created by SOCHARA at district level, during TOT training programs with follow up.
6	Additional human resources	Community health fellows; interns; volunteers from institutions and others
7	Media support (photography/ audio visual/ documentation)	SOCHARA

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