Whole-person health and development: Two South Indian initiatives

Katelyn N.G. Long, Gillian Paterson and Sara Bhattacharji

Abstract

In responding to the 2016 reformulation of the United Nation’s Sustainable Development Goals, the development community’s efforts are focused on a sweep of initiatives aiming to promote whole-society, sustainable development. The ambition of the SDGs is inspiring, but also daunting, and does not always sit easily within national models of economic development. Here we profile two organisations in the South Indian state of Tamil Nadu, that have decades of on the ground experience in whole-person development among scheduled tribes and disability communities. Both organisations serve as timely examples of ongoing holistic, whole-person health and development in the context of new ideals and economic realities.

Key words: Aid; development policies; NGO; disability; faith-based organisation

Introduction

In January 2016, the United Nations endorsed the Sustainable Development Goals (SDGs), shaping aspirations for 21st century development. The goals range from “no poverty, zero hunger, and good health and well-being”, to “decent work and economic growth, and industry, innovation, and infrastructure.” While many low-and-middle income countries (LMICs) are working to grow their economies in the context of these goals, the benefits of development can remain elusive for marginalised communities, particularly indigenous groups and chronically disabled people who are largely invisible in the ‘grand narrative’ of economic and technological advance (International Labour Office and International Disability Alliance 2015).

In this viewpoint, we use the term “whole-person development”, building on principles of whole person care (Hutchinson 2011), to mean health and development work that goes beyond the usual, goal-directed paradigms of development to incorporate psychosocial and spiritual factors that are embedded human health and well-being. To highlight this concept, we have chosen two examples of organisations from the Indian state of Tamil Nadu, both of which are working to encourage ‘whole person development’ among often-invisible groups. One, established and run by two Gandhian doctors, is in a remote, largely agricultural tribal area; the other is attached to a Christian medical college and hospital. Both groups identify faith as part

* Corresponding author: Katelyn Long knlong@bu.edu
of the inspiration behind their work, saying that their organisation and values have been shaped by the principles and practice of the belief systems to which they subscribe, namely the life, teachings and work of Mahatma Gandhi, and of Jesus. The organizations were selected by the authors due to personal exposure and are by no means the only organizations in India, or elsewhere, that embody the principles of whole-person development. Due to limited documentation on these initiatives, the following accounts are drawn from a synthesis of organisational documentation, personal observation and communication with local actors (gathered by the authors in 2017). Through the stories of these two organizations, our goal is to describe an on-the-ground concept of development practice that responds to felt needs, engages deeply with the community, uses local resources and ideas, and above all, sees health and development through the lens of wholeness, not only the absence of disease and poverty.

Wholeness in tribal villages

“India lives in her villages” – Gandhi (1925)

Over 200 km southwest of Chennai, far from the hustle of urban life, Sittilingi valley lays tucked away in the hills of Eastern Ghats. Spread across the valley over 20 ‘scheduled tribes’, also called ‘Adivasi’ – who are among India’s most vulnerable populations. Their remote locations make it particularly difficult for them to take advantage of health and social services (Hall and Patrinos 2012). As the main Indian economy roars forward, pressure to move to urban areas continually draws young people away from these communities, generally leaving behind the old, the young, and the sick.

In the early 1990s, Drs. Regi George and Lalitha Regi moved to Sittilingi. Inspired by their years working at the Gandhian University in Madurai, they were committed to lives of simplicity, service to the poor, and to spiritual integration of knowledge and practice. As doctors, their intention in Sittilingi was to reduce maternal and child mortality, although they insist they had no strategic plan, no theories of change, and definitely no grand ‘visions’ of development. Their main goal was to become members of the community and to find ways to work alongside tribal members to improve the health of women and children.

The early years were difficult. Regi and Lalitha note that they had to work hard to earn trust in the community, spending as much time sitting in people’s homes as they spent attending to births and infant check-ups. This slow work of relationship-building allowed them to meet young tribal women who had energy and capacity to be trained as community health workers (CHWs). As trust grew, the doctors and CHWs provided maternal and child care throughout the valley, and eventually, expanded to other primary care needs. Calling themselves the Tribal Health Initiative (THI), they divided the week into days spent visiting villages on foot, and days working out of a small outpatient hut in Sittilingi village. The work found financial support from varied sources, including Tamil businesses and the couple’s personal network, enabling them, slowly, to build a small medical compound. Patients paid what they could afford. While the CHWs formed the
Ten years after they started, THI paused to take stock of their work. Maternal and child mortality had reportedly dropped to some of the lowest levels in the state (Tribal Health Initiative 2017), and the medical compound was always full of people receiving care. Nonetheless, THI wanted to know how the tribal community felt about their work and where to focus future efforts. For this reason, in 2003, THI staff set out on a six-month *Padayatra*, a foot journey, going door to door in each village to speak with people in their homes. “We don’t have as many health problems now, but we worry about other things”, village members said (re-telling of the Padayatra by THI staff 2017). They explained that their biggest concerns were about farming debt amassed as a result of low crop sales and expensive trips to the (only accessible) market over 100km away. They also wanted paid work for women and access to education for their children, which required families to obtain legal status as ‘scheduled tribes’, a long and costly process that almost no one could afford.

Lessons learned from the Padayatra set THI’s course for the next 12 years. First, they helped people to complete the lengthy application for scheduled tribe status, which often involved driving back and forth between villages and district headquarters. Within a few years, nearly every qualified family had legal scheduled tribe status. This, in turn, allowed children to attend good public schools with additional support from the government for fees, transportation, and books.

THI also focused on the issues affecting farmers and women. A few farmers in the valley were already committed to organic farming practices, and together, the farmers and THI formed the Sittilingi Organic Farmer’s Association (SOFA), focused on reintroducing and preserving native crops like millet, cotton, and groundnut, as well as conserving water and soil. Over time SOFA was able to demonstrate cost savings through organic practices, attracting many more farmers to join the association. To address the challenge of selling the crops, two women’s groups were formed. Sittilingi Valley Agricultural Diversity (SVAD), bought crops from the farmers at slightly above-market price, then processed the crops into products like millet cookies, soap, and ready to use spices for sale in markets. THI’s second women’s project called *Porgai* (which in the Lambadi dialect means ‘pride’), built on the outstanding artisan skills of Lambadi women to create and sell handmade clothing and home goods. Today, SOFA has over 500 farmers and has formed into a tribal-directed company with shares owned by each farmer and their family. SVAD products are sold locally and in markets across Tamil Nadu. Porgai employs 60 women and sells products across India and internationally.

Over the years THI has faced familiar challenges of health and development work: medical staff shortage, stretched finances, and the scramble to keep pace with evolving medical technologies and regulations. Their biggest challenge has been the varying relationships with government officials, some of whom have asked for bribes, which THI adamantly refuses to pay. Despite these challenges, THI says the work
of the community propels them forward. In recent years, they have started a local school, expanded clinics in even more remote areas, and implemented yoga training to help patients with chronic disease. While the list of activities is long, Sittilingi seeks to retain a ‘peaceful atmosphere’. The pace is intentionally kept slow, alternating between clinic and project days to protect staff time, eating communally, and living locally. THI likes to say that it has ‘silently’ made a difference in among tribal families in the last 25 years (THI 2017). Although their initiatives mirror many major development priorities, the work is carried out in a distinctly local style that they say comes from working among tribal communities in a spirit of peace, understanding, trust, and justice (THI 2017).

REHAB Mela: wholeness and disability

“I came that they may have life, and have it abundantly.” John 10:10

Disability is prioritised in the SDGs, and is specifically mentioned in six of them. However, disabled people remain largely invisible in most societies – especially in LMICs, and is a major issue in India. Over fifty years ago, the Rehabilitation Institute of the Christian Medical College, Vellore (REHAB) set out to address this. REHAB’s vision was shaped by two key actors: Paul Brand, with his ground-breaking research and surgical work on the hands and feet of people with leprosy, and Mary Verghese (REHAB’s dedicated founder), herself a paraplegic and wheelchair-bound after a road accident destroyed her aspirations to be a gynaecologist. For them, (and for the many who have followed in their wake), the call to work with people excluded from full participation in their societies is described as a fundamental response to the call of Christ, who took the side of excluded men, women and children, and for whom healing involved not taking people out of society but sending them back into it (Wilson 1967, REHAB Annual Reports 1962-2016).

Vellore is a fast-growing city, 140km west of Chennai in Tamil Nadu. Its Golden draws pilgrims from across the sub-continent and is also widely known as the home of the Christian Medical College and Hospital (CMC) founded in 1900 to serve the women of India. Today, CMC includes a network of primary, secondary and tertiary care hospitals in, and around, the city – one being REHAB, located a few hundred yards from a particularly dangerous crossroads in the Vellore suburb of Bagayam.

One late afternoon in February 2017, traffic was backed up beyond the road junction. At first it looked like another accident, and then it became clear that an improbable procession of people in wheelchairs, being pushed on trolleys, or hobbling along on callipers and crutches was winding its way across the road. REHAB staff (and the authors who were observing this), described it as just like the Red Sea parting for Moses – with the cacophonous surge of trucks and buses, autos and two-wheelers stopping in their tracks to let them pass. This was the first day of REHAB’s 24th Spinal Injury Mela. These patients, ex-patients, carers and staff were processing the short distance from the REHAB Institute to the nearby Mary Verghese Institute, where the evening’s celebrations were about to begin.
REHAB’s role is to respond to the need for long-term rehabilitation among people disabled by spinal injuries, brain injuries, strokes, amputations and cerebral palsy. Once admitted, patients may remain in in-patient care for three to four months. Medical care is, of course, a priority. However, REHAB’s overriding aim is to enable people to live productive, well-adjusted lives in their own environment, and to support them as they struggle to do this. It is a deeply ‘holistic’ understanding of healing, where the involvement of families and friends is perhaps even more vital than the vocational, occupational and physiotherapies provided.

Holistic patient ‘care’ continues after the patient is discharged – as most of these patients will need regular follow-up and support. This is often made difficult by the fact that patients may live up to 100km away; travel and accommodation are expensive, and public transport often (for disabled people) very difficult. Furthermore, somebody will need to accompany them. The Mela is REHAB’s response to these challenges. For three days every year in February the organisation focuses all its resources on providing check-ups, investigations and consultations for former patients. But the Mela is more than that. It has the atmosphere of a big, three-day party: a time to re-engage with old friends and make new ones, to celebrate achievements and to share experiences with people who understand because they have been there themselves. Sports events are enthusiastically attended, with great pride in the Vellore Wheelchair Basketball Team: all members of which are former or present patients at REHAB. There are also health education and discussion sessions, and an art competition. Each day ends with a vibrant evening event, performed both by students and by people with disabilities themselves.

Around 200 patients who live within 100km of Vellore, each accompanied by a carer, and some by children who cannot be left alone, attend the Mela. It requires massive and complex organisation. Invited participants receive a ticket entitling them to the meals provided. A huge, fireproof tent is erected, with a thick layer of sand covered by a layer of heavy red cotton (comfortable for sleeping, because the sand moulds itself to the sleeper’s shape). The tent is also a comfortable place to conduct daytime sessions, which range from health education, with emphasis on difficulties (in toileting, for example) to discussions on ‘Barriers to a better life’ – the theme for this year’s Mela. When asked by the session leader what those barriers are, participants frequently mention: ‘low self-esteem,’ ‘women’s status,’ ‘laziness,’ ‘fear,’ ‘anger,’ and lack of family support.’ As one young man put it, “The most important thing is that you have to get out of the house and meet other people. But that is also the most difficult” (Mela participant 2017).

REHAB patients from all religious traditions speak of the road to recovery as being a spiritual journey as much as a medical one. It is hard to face the fact that ‘getting better’, for this group of conditions, will rarely mean ‘being cured’, in the sense that they will ever be the people they once were, or hoped to be. Nonetheless, many patients do find a new way of being – often saying “God has helped me” or “Meditation brings me peace” (personal communication with REHAB staff and patients 2016-2017). The experience of
many REHAB patients seems to resonate with a well-known poem by India’s Nobel Prize-winning poet, Rabindranath Tagore:

“I thought that my voyage had come to its end at the last limit of my power ... But I find that thy will knows no end in me. And when old words die out on the tongue, new melodies break forth from the heart. And where the old tracks are lost, new country is revealed with its wonders.” (Tagore 1912)

Discussion

The SDGs set an ambitious framework for holistic development by 2030. The scale of the goals and accompanying 169 targets can seem daunting, running the risk that development workers might, in a sense, ‘bury their heads in the sand’, fixating on goals that only pertain to their area of interest and training. We suggest that overly grand and overly narrow views of development can be equally troubling for very local actors. Here we have profiled two local ‘holistic’ initiatives that embody concepts of whole-person health and development - shaped by particular local interpretations of ‘health’, ‘healing’, and ‘wholeness’. It was not our intention here to put them on a pedestal. These are certainly not formal evaluation assessments– and we do not address the challenges and disruptions they have faced over time. Our intention is instead to highlight two local, relatively unknown initiatives that continue on despite, and perhaps slightly oblivious to, global agendas.

What lessons can we learn from the experience of these two projects? First, both projects affirm the value of the individual, no matter who they are. Second, they maintain a constant focus on the most vulnerable and least valued people in the current societal systems. Third, the focus on the individual does not lead to the exclusion of community. Rather, these initiatives build the community and strive to listen to the collective voice, in keeping with the adage ‘nothing about us without us’.

Fourth, the leaders and staff of these two initiatives consistently articulate that development takes time, requiring patience and persistence, and that ‘success’ and ‘failure’ are not defined in classical binaries. The strength of government and large-scale development programmes is that they can achieve targets in a programmatic, time-bound manner, while local organizations have flexibility to work with longer or shorter time horizons, based on the inputs of the community. We suggest that the greatest development impact might be reached when large development efforts work alongside local initiatives like the ones described here. Finally, both projects affirm that individual health is not uni-dimensional; it involves body, mind, and soul. Likewise, community health is a harmony between many interacting factors that go beyond physical and psychological factors to include the structural, social, economic, and spiritual elements of life.

Through this short viewpoint, we invite more frequent assessment (and appreciation) of local-level community initiatives. We also invite more detailed consideration of initiatives that undertake a ‘whole
person’ health and development approach – and the way these initiatives might model meaningful practice with applicability across all levels of development.

Notes

1. For a complete list of SDGs see: http://www.un.org/sustainabledevelopment/

2. A ‘scheduled tribe’ is an officially designated group of indigenous people in India. “Although Scheduled Castes’ (SCs) and Scheduled Tribes’ are sometimes said in the same breath, they are distinct social categories.” (Hall and Patrinos 2012, 2).

3. The Indian census of 2011 estimates that 2.21% of the population is living with a certifiable disability. WHO estimates that around 5% to 8%, given widespread under-reporting. In 2015, Indian Prime Minister Narendra Modi launched an ‘Accessible India’ campaign, to make universal accessibility for Persons with Disabilities (see International Labour Office and International Disability Alliance 2015).

4. A ‘Mela’ is a Sanskrit word meaning “to meet”, “gathering”, or “fair”. In India, the term is used for many types of gatherings including religious, cultural, sports, or commercial.

Notes on contributors

Katelyn N.G Long is a DrPH candidate at Boston University School of Public Health. She is currently studying the role of voluntary and faith-inspired organizations in health systems. Her other public health work has been in the areas of chronic disease prevention, adolescent health, mental health, and positive deviance in vulnerable communities. She has no formal relationship with either organization in this article, but has visited both to learn about their work.

Gillian Paterson is a Research Fellow at Heythrop College, University of London, with a special interest in the interface between faith and health. Recent publications and consultancies have focused particularly on physical disability, HIV and AIDS, and Catholic approaches to population and development. She has worked in a voluntary capacity with CMC Vellore for over 25 years.

Sara Bhattacharji is a retired professor of community medicine from CMC Vellore. Her interests and work have been in primary health care, training and supervision of village health workers, women’s development, child malnutrition and general practice. She has been involved with developing a community based rehab programme in the slums of Vellore, skilling community volunteers and people with disability to improve their quality of life. She is on the board of many community health organizations, including THI.
Acknowledgements
We are very grateful to the leaders and staff at THI and REHAB for allowing us to visit their projects, for sharing their experiences, and for reviewing drafts of this article for accuracy. Particular thanks to Drs. Regi and Lalitha, Dr. Guru, and Dr. Suranjan Bhattacharji.

References


