PROVIDING COMPREHENSIVE, PATIENT-CENTERED CARE

A Conceptual Framework for Social Support of TB Patients
DISCLAIMER

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In composing these guidelines, the authors have been diligent in their efforts to verify its content through the date of its publication (November 2015). This is a revised version of an earlier document that was developed under USAID/TBCARE II project in 2013.
Acknowledgements

University Research Co., LLC wishes to thank all the people who have collaborated on the development of this product. They have given generously of their time and their experience. Significant contributions to the technical assistance to develop of this product were made by USAID/TB CARE II team.

This product was produced under the overall direction of USAID/TB CARE II Project Director, Dr. Refiloe Matji. with valuable technical inputs from TB CARE II team including: Dr. Tamar Gabunia, Siphiwe Mndaweni, Robert Makombe, Samson Haumba, Marianne Calnan, Limbikani Kanyenda, Jebson Zingwari, and Sipho Nyathi among others. Special thanks are due to URC HQ team, Dr. Neeraj Kak and Dr. Hala Jassim, who designed the framework and provided valuable technical inputs and revisions.

Special thanks go to the Ministries of Health/National Tuberculosis Program for their inputs. Thanks are due to partners and stakeholders including World Health Organization.

The document draws on USAID/TB CARE II 2013 version and WHO background references.
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1 INTRODUCTION

Tuberculosis disease occurs most often within the context of economic and social vulnerabilities, and patients receiving TB treatment services frequently experience other psychological, social and economic problems that may interfere with their ability to complete treatment. An episode of TB may further exacerbate poverty or reduce a patient or family’s economic and social conditions, and even if cure is attained, the experience of TB can reinforce health and social disparities and increase the risk of reinfection. The effect of TB can be especially profound for patients who already experience vulnerabilities, i.e., migrants, the homeless, prisoners, people with HIV, patients with substance abuse problems, as well as social/ cultural minorities and other marginalized groups.

The context for this document is the recognition that the provision of high quality care for TB, TB/HIV and MDR TB patients requires effectively addressing the social conditions which underlie the occurrence of TB disease and which can prevent positive outcomes or can expose a TB patient to significant economic or social risk. Increasingly, our programmatic experience has demonstrated that in addition to addressing the process and content of clinical care, in order to provide truly patient-centered care, it is necessary to also address the context in which the patient experiences illness and receives care. As we move towards the post-2015 global TB strategy, the importance of moving beyond successes in clinical service delivery to better address TB patients’ holistic health and social needs is becoming recognized. The post-2015 Global TB Strategy, which was endorsed by the World Health Assembly in May 2014 includes targets around the reduction of catastrophic costs by TB patients and calls for bold policies and programs around “Social protection, poverty alleviation and actions on other determinants of tuberculosis.”

The objective of this document is to provide a framework for URC implemented TB, TB/HIV and MDR TB projects to better plan, manage, and coordinate delivery of social support and social protection services for TB patients. This guide includes lessons from existing TB social support programs,

WHY SHOULD TB PROGRAMS BE CONCERNED WITH SOCIAL SUPPORT/ SOCIAL PROTECTION?

- Social protection against the cost of illness is a central policy objective of Universal Health Coverage and the post-2015 Global strategy for Tuberculosis (TB).
- To find the missing 3 million: economic barriers are a leading reason why TB patients do not seek timely, effective diagnoses from qualified providers.
- To improve treatment outcomes: ensuring patients have the adequate, holistic support they need to complete treatment is the bed-rock of patient-centered care.
- To prevent future cases and contribute to a society free of TB: when TB no longer leads to more vulnerability and poverty, fewer people will be at risk of re-infection.
including URC supported projects, and attempts to build on these to move towards the development of a minimum package of effective social support and social protection services, with discussion around the purpose and need for different social support components, and potential partnerships with existing service providers. It is recognized that patients will require a different set of services depending on their context, including their disease profile, economic status, age, sex, and specific social conditions. This framework is not, therefore, designed to be prescriptive but rather to provide guidance to programs to review, design, and monitor social support packages to advance their TB programmatic objectives.

2 SOCIAL DETERMINANTS OF HEALTH FOR TB PATIENTS

Social determinants of health are key risk factors for TB. Key structural determinants of TB epidemiology include global socioeconomic inequalities, high levels of population mobility, and rapid urbanization and population growth. These conditions give rise to unequal distributions of key social determinants of TB, including food insecurity and malnutrition, poor housing and environmental conditions, and financial, geographic, and cultural barriers to health care access. In turn, the population distribution of TB reflects the distribution of these social determinants, which influence the 4 stages of TB pathogenesis: exposure to infection, progression to disease, late or inappropriate diagnosis and treatment, and poor treatment adherence and success (Hargreaves et al. 2011).

As public health professionals, we know that public health achievements largely depend on actions outside the health care sector (Commission on Social Determinants for Health, 2008). Tuberculosis is not an exception, but rather a leading example of a social disease
and the current TB control strategies need to be complemented with efforts to address psycho-social, economic needs of TB patients. In fact, without addressing the social and economic conditions which create vulnerability to TB, it is unlikely that we will make the improvements we need to combat the disease. In the United States and Western Europe, declines in TB rates starting in the middle of the 20th century were closely linked to improvements in social, environmental, and economic conditions of communities; indeed, reductions outpaced even improvements in treatment and lead to the conclusion that poverty reduction is one of the single most important factors in reducing TB incidence.

Providing diagnosis and treatment alone to the TB patient will not ensure that they will go on to be cured and remain healthy. Many factors combine together to affect the health of individuals and communities. In general, determinants of health include (WHO):

- The social and economic environment,
- The physical environment, and
- The person’s individual characteristics and behaviors.

Many factors come into play to affect a TB patient’s treatment outcomes and overall care:

- Personal knowledge about TB, motivation to adhere to treatment, and coping mechanisms to deal with side effects etc.
- Social and cultural support systems, including both the direct support a TB patient receives from their family and friends as well as social norms that prescribe certain behaviors based on the TB patient’s sex, age, and other categories/labels.
- Comprehensive health services- access and use of services to prevent and treat disease, such as referrals to the treatment of co-morbidities such as HIV or diabetes.
- Stable economic situation; retention of employment and income
- Physical environment requirements including transportation and housing
- Supportive community resources such as education, security/police, etc.

Many of the above mentioned factors impact on delay in seeking TB care or TB treatment outcomes (see figure 2). Thus, even ensuring that free TB diagnostics and treatment are available will not guarantee that a patient seeks out TB services. Some the barriers to care are:

- Transportation costs and distance to the facility
- Fear of financial insecurity and potential loss of employment/ work time
- Fear of stigma and loss of support from social networks following a positive diagnosis
- Gender- related norm or social norms affecting health care utilization, etc.

Thereby, social support of TB patients helps to mitigate existing barriers in receiving TB care and was defined by Gottlieb (2000) as the “process of interaction in relationships which improves coping, esteem, belonging, and competence through actual or perceived exchanges of physical or psychosocial resources”.


3 SOCIAL BURDEN OF TUBERCULOSIS

A century ago TB ravaged affluent and poor countries alike; today, rates of TB have become telling indicators of a society's wealth or poverty. At present, 95% of the 8 million new cases of TB, and 98% of deaths from TB, worldwide are in developing countries. In these regions, disease and death from TB occurs most often in the most economically active segment of the population; among the 1.5-2 million people dying annually from TB every year, 75% are between the ages of 15 and 54, with TB accounting for almost one-fifth of all deaths in this age group.

TB kills more women annually than all the causes of maternal mortality combined. Worldwide, some 900 million women of reproductive age are infected with TB, and at least 2.5 million every year develop active TB. Among women aged 15 to 44 years, TB accounts for the annual loss of an estimated 8.7 million years of life. Gender inequality also plays an obvious role. While men are more likely to have latent infection with M. tuberculosis, women are more likely to progress from infection to active disease, and poor women are less likely to receive diagnostic and treatment services (Kim JY).
4 TUBERCULOSIS AND GENDER
TB is a disease of poverty affecting vulnerable groups. The vast majority of TB deaths are in the developing world where gender inequities are all too common. In most of the world, more men than women are diagnosed with tuberculosis (TB) and die from it. However, TB is a leading infectious cause of death among women.

- In 2013, an estimated 3.3 million women fell ill with TB, of which the African and South East Asia regions accounted for nearly 70% of cases.
- Annually, about 700 000 women die of TB, and over three million contract the disease, accounting for about 17 million Disability Adjusted Life Years (DALY).
- TB among mothers is associated with a six-fold increase in perinatal deaths and a two-fold risk of premature birth and low birth-weight.
- TB in pregnant women living with HIV increases the risk of maternal and infant mortality by almost 300%.
- As tuberculosis affects women mainly in their economically and reproductively active years, the impact of the disease is also strongly felt by their children and families. The mortality, incidence, and DALY indicators do not reflect this hidden burden of social impact.
- Stigma and discrimination in some settings can result in women who become ill with TB being ostracized by their families and communities.
- Many studies found no quantitative gender-related differences in barriers and delays limiting access to TB services. When differences were identified, women experienced greater barriers and longer delays than men.

5 A CONCEPTUAL FRAMEWORK FOR SOCIAL SUPPORT
As mentioned above, the new Global TB Strategy endorsed by the World Health Assembly calls for “Bold policies supportive systems” as a pillar of TB control efforts for all high burden countries going forward. Social support refers to the person’s perception and confirmation that he/she is part of a social network that cares for him/her (WHO Companion Handbook 2015). A critical component is the need to make social protection an integral part of TB control strategies, backed by a goal of reducing financial hardship experienced by TB patients. At the moment though, there is little consensus on what comprises a social protection package for TB patients, their families and communities, or who is responsible for providing these services. Similarly, there are still relatively few programmatic best practice examples of how social support services can be organized and managed for TB patients.
According to the WHO latest guidelines for management of MDR Tuberculosis, social support is determined by access to four resource categories Figure xx (WHO Companion Handbook 2015).

Figure 3: Basic Social Support Functions

It is essential for all TB care programs to ensure access to the four social support functions described above. Patient-centered TB care model can only be implemented if health systems are prepared to holistically address all dimensions of the problem including physical, social and mental wellbeing.

The following sections outline several of the key areas of social support/ social protection that have begun to emerge in different settings. It is important to note that almost no country is as yet providing the comprehensive package of services, nor may all services be equally necessary for TB patients in all settings. There is also some overlap between the objective and method of different services listed.

6 INFORMATIONAL SUPPORT

It is strongly recommended that all patients and their primary caregiver(s) receive education about the disease, its treatment and the need for adherence to therapy. Physicians, nurses, community health workers, and other health care providers can provide education and effectively deliver key information about the disease. The information should be communicated in a clear and encouraging manner to stimulate a positive
adherence behavior. The language used by a counselor should be free of words like defaulter’, ‘suspect’ and ‘control’ which contribute to disempowering TB patients despite the good intentions of the health care providers. Any expression that would put blame exclusively on the patient as if he or she was singly responsible for failure of treatment is unacceptable.

Easy access to user friendly, culturally sensitive educational materials is very important to reinforce the information communicated verbally. For patients with literacy limitations, efforts should undertake to use e-health tools based on audio or visual support. Patients should be provided with a copy of the Patients’ Charter, describing the rights and responsibilities of TB patients, in their local language. This charter outlines the rights and responsibilities of patients, and its distribution will assist the provider in educating the patient on the disease and treatment.

Box below offers tips for delivering key information to the MDR-TB patient as recommended by WHO (Companion Handbook, WHO 2015). It also includes a checklist of information and education issues to provide to patient and family caregivers before starting MDR-TB treatment.

### TIPS FOR DELIVERING KEY INFORMATION TO THE MDR-TB PATIENT

- Always use a venue that guarantees confidentiality in communication.
- Use language that reassures mutual respect and esteem between the patient, caregivers and health care providers.
- Do not make promises that the health care service cannot keep.
- Avoid arguments and any discriminatory remarks for whatever conditions the patient has.
- Respect the patient’s right to choose.
- Teach the patient how drug-resistant TB can be transmitted (long exposure to contaminated air in crowded conditions), how it cannot be transmitted (sexual relations, kisses, sharing cutlery and clothes, etc.), and teach the essentials about household infection control measures.
- While respecting patient’s religious beliefs, explore proactively and clarify wrong notions the patient may have about the disease and its treatment, especially those that may become barriers to adherence to treatment.
- Enable the patient to counteract stigma and discrimination by reassuring that his/ her disease is not the result of any socially or morally inappropriate behavior that he/she has made in the past; and that many other patients have passed successfully through a similar experience.

### CHECKLIST OF INFORMATION AND EDUCATION ISSUES TO PROVIDE TO PATIENT AND FAMILY CAREGIVERS BEFORE STARTING MDR-TB TREATMENT

- Inform the patient about the length of treatment according to the regimen selected – often at least 20 months, but it may be shorter or longer.
- Discuss where treatment will start. If at a hospital, estimate the approximate length of time. If at home ask about the home living situation and whether or not the patient feels home treatment will be possible.
- Teach the patient about the drugs in general terms: i.e. there are at least five different anti-TB drugs, which the patient will take, of which one is an injectable agent. Try to teach the names of the drugs and show what the pills look like.
- Teach the patient about possible side-effects and the actions to take once detected, including reporting to the DOT provider, especially those with serious consequences like any hearing loss, ringing in the ears or suicidal ideation.
- Teach the patient about monitoring requirements for smear, culture and laboratory tests for early detection of side-effects.
- Make sure that patients and caregivers know how to make an appointment if they need to be seen before the next routine visit.
- Make sure they know that the DOT provider can contact a doctor urgently at any time of the day.
- Instruct them what to do in case of an emergency (like severe shortness of breath, seizure, etc.)
- Always provide a copy of the TB Patient Charter, informing the patients about their rights and responsibilities related with the treatment and prevention and control of TB;
- Inform patient and family caregivers on social support and social protection options the patient is eligible for according to the existing law in the country, including palliative and end-of-life care as needed.

**Example: Introducing android based patient education module on Tuberculosis in Georgia**

URC within USAID Georgia TB Prevention project in 2014 has developed an Android-based application for tablets to be used during the TB patients’ counseling sessions by nurses or epidemiologists. This is 21 minutes video with attractive visual accompanied by a man’s voice in Georgian language to ensure standardized delivery of the content. The Android application has Geo and time tagging functions for quality monitoring of epidemiologists performance. All community based health workers involved in TB care are equipped with tables and can use the application on a daily basis. Printed educational materials are also widely available for recently diagnosed TB patients and their family members so they can consult them as needed.

7 **EMOTIONAL SUPPORT SERVICES**

Tuberculosis is often associated with a severe or upheaval in a patient’s life, and can have profound psychological and social effects. The multiple burdens a patient and their family may experience relate to deal with stigma, isolation, feelings of helplessness, familial emotional trauma, and other reactions to the disclosure of the diagnosis as well as medication side-effects.

Unfortunately, stigma is seen to play a big role in the experience of TB illness. This issue may arise especially among women in some communities, where they not only lack an access to health care services, but may also suffer from social isolation, rejection from their families, especially husbands, harassment and etc. as a result of TB.
The interplay between TB and mental illness

A review of existing literature related to mental health and TB conducted in 2013 identified rates of mental illness of up to 70% in TB patients. TB medications known to have significant adverse psychiatric effects include cycloserine, and drugs such as rifampicin have been seen to reduce the effectiveness of anti-psychotic medications. TB providers need to be aware of the possibility of encountering patients with undiagnosed mental health disorders, and of the possible impact of TB drugs on the mental health of patients. (Doherty AM, Kelly et al)

In more severe cases, a patient may experience with psychiatric issues such as depression or anxiety either due to underlying conditions, factors related to their mental state during treatment, or due to drug side effects. Conversely, patients with existing mental health disorders who get sick with TB may require specific treatment interventions. TB and mental illness have many common risk factors in some settings, i.e., homelessness, substance abuse, and the presence of significant co-morbidities such as HIV.

Psychosocial support is a crucial component of TB treatment. Adequate counselling, psychological support, and referral to mental health services facilitate not only completion of complicated treatment, especially in case of MDR TB and further rehabilitation after treatment, but supports mental wellbeing and enhances coping mechanisms of patients.

Several components of psychosocial support are used for TB patients, i.e.:

- Individual counseling or case work
- Support groups or self-help groups
- Community engagement to support TB patients
- Provider training around interpersonal counselling and identification of mental health needs

Some TB control programs use some other types of psychosocial support like recreational excursions, symbolic celebrations, family workshops which could be considered as parts of support groups and social mobilization.

Box below presents a model for organizing support groups or one-to-one counseling session in support of MDR-TB patients (Companion handbook, WHO, 2015).

**PSYCHOLOGICAL SUPPORT TO MDR-TB PATIENTS THROUGH PEER-TO-PEER AND GROUP SUPPORT**

- A counselor, social worker or someone trained in facilitating support groups should facilitate the meeting.
- A trained drug-resistant TB community nurse or health worker may co-facilitate the group.
- Clear eligibility criteria should be created for participation in each support group:
  - Participation should be generally reserved for patients who are sputum negative and are no longer infectious, especially if the meeting cannot take place in an open space.
  - Cured patients may also be invited to support groups, as they provide hope to patients who are still on treatment.
Some groups may be reserved for patients with serious psychosocial issues and may require a facilitator with psychiatric training.

Other groups may be largely self-organized and appropriate only for patients without psychiatric issues.

- Support groups may need help in inviting participants, finding a safe meeting place and other organizational issues.
- At the end of each support group meeting, the facilitator and co-facilitator should stay behind to discuss and analyze the lessons learned in the process and plan the next session.

Example: The community-based groups led by women leaders were created in Bihar, India with a support of the Axshya Project. Women in villages meet monthly and discuss various concerning issues, including TB. They encourage women in villages to get tested for TB if they are symptomatic, and to seek treatment.

Example: In Malawi, within the Mwanza AIDS Support Organization (MWASO), 3 to 10 non-infectious patients and former TB patients form “TB clubs”. They main purpose of creating such groups is to support each other by attending outpatient visits together, support each other with treatment adherence, identify possible adverse drug reactions in other members and etc.

8 Companionship Support

Companionship support is about providing care that intends to strengthen self-esteem through empathy, trust, encouragement and care, among others, and that helps to deal with the psychological challenges in life. Availability of a companion helps the patient to cope with the disease, and stigma and discrimination associated to it. Former TB patients trained as peer educator can provide good companionship support.

In many countries TB programs increasingly engage cured patients into the TB case management. “Expert patients” can act both as friend and educator. However, for doing so they have to be equipped with specific knowledge of TB care standards and the rights and responsibilities of people with tuberculosis. Health care workers can act as intermediaries between patients and community champions. Moreover, they are well placed to offer direct counseling and support to TB patients when they need to better understand the nature of disease, deal with severe side effects related to TB treatment and living difficulties in daily life. “Working together, a health worker, a peer supporter and the patient can facilitate wider participation, fostering a spirit of collaboration and innovation towards reducing stigma, and reaffirming that drug-resistant TB can be successfully treated within a framework of mutual respect among all stakeholders.” (Companion handbook, WHO 2015).
Example: Mobilizing religious leaders to join the fight against TB in Georgia

A new initiative launched in 2013 to involve the religious community in Georgia is demonstrating the effectiveness of involving the clergy and religious institutions in combatting TB. The Georgian Orthodox Church is widely respected throughout the country, as both an authority and a support system. Working with the USAID TB Prevention Project and the Center of Bioethics Studies and Culture, the Georgian Orthodox Church has trained clergy members to raise awareness in their parishes to reduce community transmission of TB, to provide spiritual support to TB patients to improve adherence, and to increase access to TB services in monasteries. Through this initiative, Church leaders are able to reach socially vulnerable populations through anti-stigma information campaigns, using their well-respected position in the community to take an active role in educating community members about the spread of TB, as well as about its treatment and prevention in order to diminish TB-related stigma.

9 Material Support to TB Patients

9.1 Access to basic health and TB services

With the adoption of formal Universal Health Coverage (UHC) policies in many high burden TB countries, health insurance programs have come to form a critical part of the social protection. However UHC’s three main pillars such as coverage, access and use, and quality of services have still some limitations, creating gaps in TB services. Shrinking healthcare budgets, inefficient delivery systems, poor service quality in developing countries oftentimes make “free” health care delivery system impossible, and in practice, services are never free. Moreover, UHC in different countries have some restrictions such as coverage of patients only from formal sector, requirements of possession of IDs, and limited coverage of MDR TB which jeopardize further access of most vulnerable groups to TB care. A state budget for TB programs (either within UHC package or vertically funded) is often limited to providing basic diagnostic and treatment services while access to a comprehensive psychosocial support remains uncovered. Many countries do not have sufficient private health insurance programs, or their schemes do not cover TB diagnosis and treatment. Developing a role of insurance providers in TB care, with mechanisms in order to provide direct benefits to TB patients would be an important agenda for ensuring access to health services.
In some places, Community-Based Health Insurance (CBHI) schemes are available to and may assist patients to defray the expenditures related to accessing and adhering to treatment. CBHI schemes are often local initiatives that build on traditional coping mechanisms to provide small health insurance products specially designed to meet the needs of low income households. They are typically voluntary schemes, and are based on concepts of mutual aid and social solidarity.

**Example:** In 1995 the Cambodia Health Committee (CHC) undertook a successful village banking initiative to support TB patients and their families and to partner microfinance with TB cure and adherence. CHC provided loans for small income-generating projects in Svay Rieng and Kampot provinces linked to its community-based TB programs. Profits from the village banking program were used further to fund village health agents, who identified TB patients, as well as delivered basic health education. The program reached more than 13,000 people across seven provinces in Cambodia, achieving very high payback rates among TB patients participating in the program with 100% adherence to TB medicines. The initiative further grew onto an expansive community-based health insurance program, which entitles members to health care coverage for all medical costs for services incurred at contracted health centers and referral hospitals. Moreover, it covers non-medical costs such as emergency transportation and funeral expense should a member pass away.

### 9.2 Financial Support to Encourage TB Treatment Adherence

The financial burden of TB for a patient and his/her family has an impact on both their overall economic welfare and their ability to maintain treatment until cure. Even when diagnosis and treatment services are provided free of charge, numerous costs may be faced relating to accessing and maintain treatment. On average, TB patients in low- and middle-income countries face medical expenses, costs for seeking/staying in care, and income loss equivalent to more than 50% of his or her annual income (WHO).

In general, patient financial support systems aim to enable patients to access treatment without negative financial consequences and to avert further slide into poverty by protecting and building their financial, physical and human capital assets. Some examples of direct economic assistance are program incentives, transportation reimbursements, and treatment allowances. Cash transfers can be unconditional, without any type of obligation to be met, or conditional, with some behavioral requirements like treatment adherence. Financial support may be provided through routine payments to a patient or their caregiver, in cash or through cash transfer systems.
9.3 Indirect economic assistance for treatment support

As an alternative or in conjunction with direct financial assistance to patients, indirect economic assistance can be provided through the distribution of food parcels, food or travel vouchers or other goods aimed at making it easier for patients to receive treatment by overcoming barriers such as housing or transportation difficulties. Different examples of what are variously called enablers or treatment support/motivational packages given by various program implementers to TB patients on treatment may target:

1. Transportation: bus tokens, passes, taxi vouchers, (may be offered instead of on in conjunction with transportation reimbursement with cash transfers described above). Every effort should be made to consolidate the trips required every month of TB treatment. Patients should be supported according to individual need considering geographic location and method of transport.

2. Stable housing: shelters, rent assistance, other housing programs (eg. Churches). Some TB patients might be needed in temporary accommodation if homeless, have very difficult family situations, patients who are too ill to go home, but are too well to be in the hospital, those who live in very remote areas.

3. Other material needs: hygiene kits, clothing and/or footwear, newspapers, board games, or other household goods.

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**Example: Mobile cash transfers for MDR TB patients in Bangladesh:**

Through the TB CARE II project, MDR TB patients receive allowances – small monetary payments – to help them buy extra food to support good nutrition during their treatment. TB CARE II, in partnership with Dutch-Bangla Bank, Ltd. (DBBL), sends monthly allowances directly to patients and providers via mobile banking services. The mobile banking system has made life easier not only for the patients and providers, who can now access their funds with a quick visit to an ATM or banking agent.

**Example: Cash incentive to all TB patients to encourage good treatment adherence in Georgia**

The Georgia National TB Program with support of the Global Fund TB Grant and USAID Georgia TB Prevention Project implemented by URC has introduced cash incentives scheme for both MDR and regular TB patients. A patient receives money based on DOT attendance data analyzed on a weekly basis. The electronic TB data management system is used to track daily DOT attendance, generate the list of eligible patients and authorize money transfer from the state treasury to a patient’s bank account. The effectiveness of the scheme has yet to be evaluated. However, early findings indicate that patients tend to improve treatment compliance if cash is provided for a daily visits to health facilities.
In addition, a critical component of patient support addresses nutritional needs. Under-nutrition is considered as a risk factor for TB, and can also be as a consequence of TB. There is as yet little evidence showing that additional nutrition support improves TB-specific outcomes, but low body mass index as well as lack of adequate weight gain during TB treatment are associated with an increased risk of TB relapse and risk of death.

The WHO Nutrition Guidance Advisory Group recommends five guiding principles to consider for TB care and addressing nutritional needs.

- **Key principle 1.** All people with active TB should receive TB diagnosis, treatment and care according to WHO guidelines and international standards of care;
- **Key principle 2.** An adequate diet, containing all essential macro- and micronutrients, is necessary for the well-being and health of all people, including those with TB infection or disease;
- **Key principle 3.** Because of the clear bidirectional causal link between undernutrition and active TB, nutrition screening, assessment and management are integral components of TB treatment and care;
- **Key principle 4.** Poverty and food insecurity are both causes and consequences of TB, and those involved in TB care therefore play an important role in recognizing and addressing these wider socioeconomic issues;
- **Key principle 5.** TB is commonly accompanied by comorbidities such as HIV, diabetes mellitus, smoking and alcohol or substance misuse, which have their own nutritional implications, and these should be fully considered during nutrition screening, assessment and counseling.

Among the basic recommendations to address nutritional needs of TB patients include:

- Conducting an initial nutrition assessment of TB patients with further monitoring
- Providing ongoing counseling for patients on their nutritional status
- Management of severe acute malnutrition should be treated according to national guidelines and WHO recommendations
- Management of moderate undernutrition for TB patients who fail to regain normal Body Mass Index (BMI) after two months of TB treatment or appear to lose weight during TB treatment should be evaluated for a proper treatment adherence and other comorbidities. If indicated, these patients should be provided with locally available nutrient-rich or fortified supplementary foods. Special categories of TB patients such as children who are less than 5 years of age should be managed as any other children with moderate undernutrition. Pregnant women with active TB, patients with MDR TB should be provided with locally available nutrient-rich or fortified supplementary foods.
- Micronutrient supplementation. All pregnant women as well as lactating women with active TB should be provided with iron and folic acid and other vitamin and minerals to complement their maternal micronutrient needs. In situations when calcium intake is low, calcium supplementation is recommended as part of antenatal care.

The program considering provision of food packages should design them according to World Food Program (WFP) guidelines for HIV patients starting antiretroviral therapy and TB patients starting treatment. The packages might include:
- Cereals (maize, rice, sorghum, millets, etc.)
- Pulses (peas, beans, lentils, etc.)
- Oil
- Sugar, salt
- Animal products (canned fish, beef and cheese, dried fish)
- Dried skimmed milk.

Example: Promoting treatment adherence through food incentives in Kyrgyz prisons

Economical support as an incentive mechanism is widely used in TB control program in the prison settings of the Kyrgyz Republic. Inmates on TB treatment receive motivational food packages in a weekly basis based on their adherence during that week. Such social support packages are supported by international partners, mainly by the International Committee of the Red Cross, Doctors Without Borders.

Example: A package of patient support incentives in Russia

One example of patient incentives is from three Russian oblasts (Ivanovo, Orel, and Vladimir). Since 2000 TB outpatients were given a combination of food packages, hot meals, transport reimbursement, hygiene packages, and clothing based on their continued clinic attendance and observed treatment. Patients were eligible to receive incentives if they do not interrupt their treatment and denied when they missed one week or more of TB treatment intake. This intervention helped with a decrease of default rate, i.e. default rate in Orel and Vladimir were between 2 and 6% in 2004, down from between 15 and 20 percent when the program began in 1999.
10 SOCIAL SUPPORT TO MDR/DR TB PATIENTS DURING PALLIATIVE CARE

10.1 Providing palliative care to MDR/DR TB patients

Despite availability of effective treatment options, MDR TB remains a life-threatening condition associated with the high mortality rate. When all treatment alternatives fail and there is no cure possible, TB programs increasingly recognize palliative and end of life care as an important part of the continuum of care for all MDR-TB patients.

The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” (WHO)

An important part of palliative care is end-of-life care. End-of-life care usually refers to the care of a person during the last part of their life, from the point at which it has become clear that the person is in a progressive state of decline. In clinical medicine, the “end-of-life” can be thought of as the period preceding an individual’s natural death from a process that is unlikely to be arrested by medical care (Lamont et al. 2005). In organized health care settings end-of-life care can be provided at patient’s home, hospitals, nursing homes or hospices.

Historically hospice has meant a place of shelter for weary and sick travelers returning from religious pilgrimages. The role of hospice has changed for the last few decades in a way that contemporary health care systems consider hospice to be a special concept of care designed to provide comfort and support to patients and their families when a life-limiting illness no longer responds to cure-oriented treatments. A principal aim of hospice is to control pain and other symptoms so the patient can remain as alert and comfortable as possible. Hospice services are available to persons who can no longer benefit from curative treatment. The typical hospice patient has a life expectancy of 6 months or less. Patients’ families are also an important focus of hospice care, and services are designed to provide them with the assistance and support they need.

The provision of social support services becomes even more important for MDR TB patients whose treatment turns out to be unsuccessful and the decision of suspending TB specific treatment is made. Besides symptomatic treatment to alleviate suffering these patients should receive social, psychological and spiritual support to ensure that their needs are comprehensively addressed.

Once the clinical team decides to suspend TB treatment medications as evidence on treatment failure is quite strong, a clear plan should be prepared for helping the patient and the family to understand and accept the reasons for such decision. Box XX outlines social support framework for MDR-TB patients during palliative care.
10.2 Social support to bereaved families

The right approach to treatment of patients with life-threatening conditions when death is unavoidable emphasizes symptom management, and supportive care for patients and their families before and after death.

A comprehensive social support should include a bereavement assessment with the family after unavoidable loss occurs. All psychosocial aspects should be considered including the following:

- Stigma that may prevent the bereaved sharing the grief
- Fear of TB infection
- Absence of Social support
- Whether loss or illness affected social wellbeing of the family
- If there are any social benefits available for the family if deceases was bread winner
- Availability of child care services if appropriate
Social counseling should be non-judgmental. The counselor through compassionate listening have to allow the opportunity for the expression of feeling, thought and experiences. The issues such as depression, anxiety, fear, stigma, superstitions, isolation, loneliness and rejection should be explored and referral to mental health provider organized if bereavement signs are more severe than expected.

11 LINKAGES WITH OTHER TREATMENT, SOCIAL SUPPORT AND DEVELOPMENT SERVICES

11.1 Networking care for TB patients at the community level

Unfortunately, often TB disease does not occur alone. Patients may have numerous of other co- morbidities such as HIV, substance abuse, diabetes mellitus, chronic lung diseases, viral hepatitis, STIs, etc. Mechanisms for delivery of integrated tuberculosis care and other services need to be established not only to address medical issues, but also keep in mind concurrent social care and support needs. Implementing integrated services is intended to increase access to services, improve the timeliness of service delivery as well as increase the effectiveness of efforts to prevent infectious diseases and disorders that share common risk factors, behaviors, and social determinants. Comprehensive, integrated models of care can be reached by provision of multiple services at a single venue or through coordination of referrals for services delivered at multiple venues. Outreach programs, HIV counseling, access to harm reduction activities and opioid substitution therapy are some of the examples of networked care, especially for patients at the community level.

As decentralized treatment programs for TB and MDR TB expand, coordination between community-based health and social services is important to leverage resources, provide adequate support to patients and their care givers, avoid duplication and provide patient-centered care.

**Conducting mental health screening for TB patients**

A programmatic intervention may include introducing a simple mental health screening questionnaires for providers of high risk patients or for patients exhibiting potential mental health issues. Referrals for counselling or other mental health services may be provided, if available. Example: Mental Health Assessment Tool for TB Patients: Heartland TB Center.
11.2 Income generation

On average, 60% of the total TB economic burden can be attributed to income loss [T. Tanimura et al]. As discussed above, providing financial support to defray the costs of TB treatment is critical, but loss of income as a result either of loss of employment due to illness or time away from work to attend the clinic can also be highly detrimental to a patient or family’s economic wellbeing. The benefits of income support to the individual and his family may not be immediately quantifiable as economic returns occur a later point of time and depend on many external factors, but can impact positively on self-sufficiency and income-generation.

While TB programs and TB providers may not be in a position directly support income generation for TB patients, some steps may be considered:

- Coordinating treatment and monitoring appointments around a patient’s work schedule
- DOTS provider may assist the patient to discuss their treatment with their employer and may provide counselling to dispel myths or stereotypes
- Coordination or referrals for TB patients to other income generation programs such as Microcredit loans, Vocational training/training programs, or microenterprise activities
- Conducting outreach with civil society to identify community services which might benefit TB patients

The benefits of addressing a TB patient’s need to ensure that a regular income is maintained during treatment, in addition to helping reduce the likelihood of catastrophic expenditures and negative financial impact, can also to improve mental health and the likelihood that a patient with interrupt treatment when they start feeling better in favor of work opportunities.

Figure 5: Examples of integrated services
Example: The Innovative Socio-Economic Interventions against Tuberculosis (ISIAT) project was implemented in Lima, Peru covering 2078 people in 311 households of newly diagnosed TB patients for up to 34 months. The activities included microcredit loans, vocational training and microenterprise activities such as raising animals (rabbits and chicken) and home-based manufacturing (e.g. foodstuffs, recycling, greeting cards, knitting, weaving, jewelers, toy and handicraft manufacture). These interventions were designed to diminish economic barriers to TB care and appeared to considerably increase uptake of the TB control services that the National Tuberculosis Program offers free of charge with social and nutritional support. This project provided evidence that socio-economic interventions can positively impact TB control activities.

Example: An NGO in Tanzania MUKIKUTE has created different projects for income generation, these included: a drama club, which has been used for community sensitization as well as it usually lent out in different occasions, making “tie-die” clothes (batiks) for selling, farming (vegetables), livestock (chicken, goats), production (soap making, bread, food processing), enterprising (fishing, bricks making).

The Engage TB approach by WHO focuses on integrating community based TB activities into the work of NGOs and other civil society organizations has a greater role on supporting economic independence. Network and collaboration with NGOs to empower TB patients, to make linkages to employment opportunities, vocational training is essential. Above all, WHO is developing a post-2015 Global TB Strategy, which considers a high priority for the need for all countries not only to progress towards universal health coverage to ensure “universal access to needed health services without financial hardship in paying for them”, but also social protection mechanisms for “income replacements and social support in the event of illness”.

Vulnerability is defined as, ‘a set of factors that result in a reduction in well-being (decreased quality of life, increased morbidity/mortality), associated with infections such as TB, malaria and HIV’ [Vulnerability and Health Alliance]. Groups which are especially vulnerable to TB vary according to the context, and the degree and type of vulnerability results from several overlapping factors ranging from biological, socio-economic and environmental factors.

**Figure 6: Factors influencing to vulnerability**

12.1 The major TB vulnerable groups and social support interventions:

**Migrants**

Migrant categories:

- Internal migrants: rural to large cities
- Cross-border population movements: mostly economically driven
- Floating population: homeless, urban slums, etc
- Labour migrants, i.e., miners
- Refugees
- Itinerant people
Challenges and needs:

- Lack of access to health care services;
- Lack of knowledge of possibly existing free of charge TB diagnosis and treatment;
- Illiteracy;
- Lack of familiarity with local language;
- Legal issues, i.e. absence of IDs, irregular residence status, work permits, social security documents, etc;
- Poverty;
- Housing;
- Poor working and living conditions;
- Financial issues;
- Food insecurity;
- Absence of job or instability in employment;
- Cultural beliefs;
- Poor health-seeking behaviours;
- Psychological distress;
- Stigma & discrimination;
- Social isolation

Social support interventions:

**Informational support**

- Educational materials on TB risk factors and early signs and symptoms

**Emotional support**

- Psycho-social support with individual counseling, case management, group activities, self-help groups

**Companionship support**

- Linkage with legal authorities in order not to jeopardize access to TB care;

**Material support**

- Ensuring access to health care:
  - Advocacy for health insurance for migrants to cover comprehensive and complete TB diagnosis, treatment and care;
  - Advocacy for improvements in national legislation which improves migrants’ access to TB services, regardless of legal migration status;
  - Mobilization of community-based health insurance schemes
- Providing temporary shelters, housing for those in need, also to ensure TB infection control;
- Nutritional support: food packages,
- Hygienic kits;
• Supporting economic independence through vocational training, microenterprise activities, etc;
• Addressing other financial needs: transportation reimbursements, bus tokens to reach TB health facilities;

Prisoners (current and former)

Challenges and needs:
• Lack of access to comprehensive health care services;
• Existing co-morbidities (HIV, IDU, Hepatitis B,C,STI, mental disorders, malnutrition, etc)
• Food insecurity;
• Housing issues for former prisoners;
• Poor living conditions and overcrowdence;
• Employment issues for former prisoners;
• Legal issues, i.e. absence or lost IDs, mainetenance of periodical report to police for newly released;
• Illiteracy;
• Lack of motivation;
• Absence or lack of family support;
• Psychological distress
• Stigma & discrimination;
• Social isolation;

Social support interventions:

Informational support
• Availability of TB specific educational materials in prisons

Emotional support
• Counselling, case management;
• Group works, support groups
• Peer education and peer counseling

Companionship support
• Linkage with legal authorities in order not to jeopardize access to TB care;

Material support
• Ensuring access to health care:
  o Establishing linkages between prison health and civilian health facilities, ensuring referral system, consultations of specialists unavailable in prisons from civilian sector;
• Ensuring access to TB prevention, diagnosis, treatment and rehabilitation within prison settings;
• Access to symptomatic drugs especially for MDR TB patients to address side effects;
• Access to integrated health care services to address existing comorbidities, i.e. access to harm reduction program, OST, ART, co-trimoxazole preventive therapy, etc;
• Treatment follow up in civilian sector for released patients;
• Ensuring access to TB care for former prisoners
  • Addressing material needs:
    o Food provision, especially to undernourished patients;
    o Provision with hygienic kits;
    o Provision of clothing in case of need
  • Adressing other financial needs for former prisoners by providing transportation reimbursement to TB health care facilities;
  • Providing temporary shelters for former prisoners on TB treatment in case of need;
  • Supporting economic independence for former prisoners through vocational trainings, programs, microenterprise activities, job opportunities, etc

**PLHIV:**
Challenges and needs:

• Constrains in access of comprehensive integrated health care;
• Food insecurity;
• Possible other comorbidities (TB/HIV + IDU, viral hepatitis);
• Lack of family support;
• Psychological distress;
• Stigma & discrimination

Social support interventions:

**Informational support**

• Access to educational resources on interaction between TB and HIV

**Emotional support**

• Individual counseling on treatment co-ordination, infection control etc;

**Companionship support**

• Links to HIV patient support networks

**Material support**
- Ensuring access to health care:
  - Access to integrated TB/HIV health care services, i.e. availability of ART, co-trimoxazole preventive therapy, etc
  - Access to other integrated health care services for other possible comorbidities (TB/HIV+ IDU, viral hepatitis, malnutrition, etc);
- Supporting economic independence through vocational training programs, microcredit loans, microenterprise activities;

**Injecting drug users:**

Challenges and needs:
- Legal issues;
- Constrains in access of comprehensive, integrated health care;
- Lack of access to harm reduction programs, opioid- substitution therapy, etc;
- Possible other comorbidities (TB/IDU+ HIV, viral hepatitis, mental disorders);
- Lack of family support;
- Employment insecurity;
- Housing issues;
- Mental health challenges;
- Social stigma and discrimination

**Social support interventions:**

*Informational support*
- Access to educational resources on TB high risk groups

*Emotional support*
- Individual counseling;
- Group works, support groups, anonymous groups;
- Mental health screening and referrals to services;

*Companionship support*
- Addressing legal issues: advocacy for decriminalization of IDUs by treatment instead of imprisonment;

*Material support*
- Ensuring access to health care:
  - Access to integrated health care services: TB treatment along with harm reduction services such as needle exchange program, access to OST, and other possible options of drug dependancy care;
o Access to other TB integrated health care services for other possible comorbidities, i.e. TB/IDU+ HIV, viral hepatitis, etc;
  o Access to Naloxone;
  • Addressing material needs:
    o Food packages
    o Hygienic kits
    o Clothing in case of need;
  • Supporting economic independence through vocational training, microenterprise activities;

Children:

Challenges and needs:

  • Pediatric TB is often overlooked in NTPs;
  • Most of the time get TB from adult family members;
  • An important role and commitment of a caregiver;
  • Food insecurity;
  • Withdrawal from schools and other formal educational institutions due to TB

Social support interventions:

Informational support

  • Advocacy for provision and access to education for children with TB;

Emotional support

  • Age appropriate patient education and counseling along with caregiver counseling
  • Introduction of family-centered care approach;

Companionship support

  • Advocacy for recognition of pediatric TB as an important part of NTP with ensuring access to specialized TB care;
  • Include the needs of children in research, policy development and clinical practices;
  • Social support interventions to caregivers:

Material support

  • Nutritional support:
    o Ensuring adequate nutrient intake on the basis of locally available and affordable foods;
    o Nutritional supplementation cannot be given directly to an infant under 6 month of age, but can be provided for the lactating mother;
Nutritional support should include early efforts to continue breastfeeding where possible;
- Addressing other material needs: hygienic kits
- Reimbursement of transportations costs;

**Women:**
Challenges and needs:
- More limited access to health care;
- Ignorance of TB symptoms as a result of fear to be abundant by husband or family members;
- Financial dependance and insecurity;
- Cultural beliefs;
- TB and pregnancy;
- Psychological distress;
- Stigma and discrimination

Social support interventions:

**Informational support**
- Availability of TB educational materials for general public in common areas

**Emotional support**
- Individual counseling;

**Companionship support**
- Self-help, support groups for women;

**Material support**
- Ensuring access to health care:
  - Basic access to health care with tolerance to cultural specificities, availability of women health care providers;
  - Addressing gender based issues in certain societies where women do not make the decision to seek healthcare no matter how ill they are;
  - Access to integrated health care, i.e. TB+pregnancy, etc;
  - Community- based insurance schemes;
- Empowerment of women by supporting economic independence:
  - Microcredit loans;
  - Vocational programs;
  - Microenterprise activities;
- Addressing material needs:
  - Food packages;
Hygienic kits;
- Clothing in case of need;
- Providing temporary shelters, i.e. in rehabilitation centers for women in case of need;
- Addressing other financial needs:
  - Transportation reimbursements to health care facilities, etc;

**Ethnic minorities**

Challenges and needs:
- Limited access to health care;
- Employment insecurity;
- Financial insecurity;
- Language and cultural barriers;
- Marginal social status; legal and bureaucratic barriers;

Social support interventions:

**Informational support**

- Translation/ adaptation of messages and information in local languages

**Emotional support**

- Social counselling

**Companionship support**

- Linkages to support networks and organizations working ethnic minorities

**Material support**

- Ensuring access to health care:
  - Advocacy for UHC of TB care along with general population without depriving of any rights of ethnic minorities;
  - Possibilities for community health coverage schemes to cover along non medical expenses;
- Supporting economic independence through vocational training, microenterprise activities, microcredit loans
Supporting patient caregivers

Another group that can experience the impact of TB disease severely is the family members or other persons who are called on to support and assist a patient through the long and complicated treatment process. Whether the parent of a sick child, or a spouse, sibling or extend family member, these persons may similarly experience considerable challenges related to loss of income and time away from work, stress and anxiety as they view their loved one’s illness, fear of infection, stigma or social isolation due to their family member’s TB status, and the strain of continually providing care.

Where possible, social support services should be extended to include this group as well. Psycho-social counseling, financial support packages, and direct benefits may be structured to take into account the person responsible for getting a TB patient to their appointment, overseeing their daily care, helping them cope with side effects and encouraging them to stay on their treatment until cure.

13 ORGANIZING SOCIAL SUPPORT SERVICES

Direct service delivery vs. developing a coordinated service network

Supporting TB patients can be done directly by the TB services providers: either through the National TB Program, clinic staff and DOTS providers, or through NGOs and organizations targeting TB patients; i.e., community treatment supports or DOTS workers. Several countries have taken the step to incorporate support programs, often based around incentives for treatment intake and adherence. Many of these programs incorporate economic support as a performance-based financial or material incentives for patients to complete their TB treatment. For this discussion, incentive is defined as “all financial or material rewards that patients and/ or providers receive, conditional on their explicitly measured performance or behavior” (definition by Alexandra Beith and her colleagues).

Whether provided through direct financial incentives or incentives involving material support, one danger of offering such incentives to encourage patients to be tested or to continue treatment is that some beneficiaries might misuse or react by engaging in practices that allow them to continue to qualify. These may be unintended effects of such incentives and proper establishing of systematized monitoring system to identify and correct them are essential parts of program design and implementation.

Another concern which may arise in relation to incentive schemes is one of sustainability. When services are provided through donor support or administered by NGOs or technical assistance partners, maintenance in the long term and the potential to transfer responsibilities or the management and financing of the incentive programs to the local authorities or a local organization needs to be addressed.
However, in most cases it is unlikely that a TB program or organization alone will be able to provide the comprehensive range of social support services discussed above. Rather, programs and providers may focus on developing coordination mechanisms and linkages with other services, aimed at fostering a network of services including the TB facility as well as sources of support outside the TB program. There will be many players in TB control or a particular setting including governmental, non-governmental organizations, international partners, community-based initiatives, and others. No single entity will be able to address all different types of patient’s social needs, but each organization should tapped to refer, link and give information to assist those needs.

**Example: Linking with the passport issuing authorities to renew lost IDs for TB patients in the prison system**

Assistance with obtaining a national identity card for prisoners on TB treatment before they will be released is a good example of such network support., for example, in St. Petersburg, Russia as a part of comprehensive needs assessment approach inmates were asked on what would them motivate to finish their treatment after release. The most highly valued incentive was obtaining of documentation, ID cards for further opportunities to work, for housing, accessing public services. Lack of ID cards has a greater likelihood of police harassment and re-incarceration.

### 14 Considerations for Program Planning

#### 14.1 Partnerships and types of service organizations

For efficient and effective social support programs, it is essential to develop a legal basis for provision of social assistance to beneficiaries, create an institutional framework with linkages between TB facilities and other partners which could also assist in support of TB patients.

A low demand for social support interventions and limited involvement of social workers in TB care continuum result in inadequate competencies necessary for effective TB case management. Capacity building of social service staff is warranted to sensitize social service providers about specific needs of TB patients and their families. Relevant professional bodies and academic institutions should be actively involved in developing social care standards and training programs incorporating aspects of TB and MDR-TB management.

Establishing of a partnership network is a key activity for collaborating with other stakeholders involved in TB programs. Moreover, these networks build a basis for referral relationships between organizations to respond in a comprehensive way for patient’s social needs. Some of the essential blueprints for productive partnerships are:

- The relationships between organizations, referral procedures and common activities between service providers are formalized and stakeholders agree on procedures
- Identify an organization to take a leading role as a coordinating organization for a particular activity
- Identify existing gaps in services and take steps to bridge them
- Seek out new partners, but do not underestimate existing ones
- Clearly identify the scope of work your partnership will undertake

**Figure 7: Partnership for Social Support**

**Table: TB Social Support partnership models**

<table>
<thead>
<tr>
<th>Type of Partnership</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Support Networks</td>
<td>Information sharing partnerships</td>
</tr>
<tr>
<td>Social Support Task Forces</td>
<td>Partnerships for short-term problem resolution</td>
</tr>
<tr>
<td>Social Support Advisory Committees</td>
<td>Joint planning and strategic partnerships</td>
</tr>
<tr>
<td>Social Support Coalitions</td>
<td>Joint planning and coordinated action</td>
</tr>
<tr>
<td>Social Support Collaborations</td>
<td>Joint planning for collaborative action</td>
</tr>
</tbody>
</table>
Some scopes for partnerships are:

- Advocacy for inclusion indirect costs such as sick leave allowance, including temporary disability allowances especially for MDR TB patients.
- Improvement of employment protection to enable patients to be able to return to previous positions once they are cured and clinically fit to perform their assignments as well as advocating for regulations and policies that mandate employers pay employees (a portion of) their designated salary while they are on sick leave.
- Engagement of social workers and social welfare systems to assist migrants, ethnic minorities, former prisoners, vulnerable children, and others to navigate legal and organizational obstacles to receiving care.

14.2 Steps for Getting Started

Developing an effective social support network for TB patients requires considerable effort and resources, but is vital to making any long term impact against the disease. Some of the steps involved are captured in the figure below.

A key starting point is to map the needs and vulnerabilities of TB patients in a given setting. This may be done in two steps, including:

A. Identify the demographic profile of TB patients.

This includes collecting information on the key characteristics of the TB patients in a given areas, and mapping the frequency of TB disease relative to certain demographic profiles to identify persons with high risk of TB. Key demographic information may include:

a. Age  
b. Sex  
c. Housing status  
d. Employment  
e. Primary language  
f. Socio-economic status  
g. Frequency of other key co-morbidities  
h. TB status- DS TB, DR TB, re-treatment

B. Identify patient support needs

Recognizing that not all TB patients will have the same set of vulnerabilities and will require the same package of services, a next step is to identify the key challenges TB patients face relative to accessing and adhering to treatment. This may be done through patient, provider and care giver interviews or focus group discussions and/or targeted assessments, death audits, default surveys or similar exercises geared at identifying the specific barriers patients experience in obtaining diagnosis or maintaining treatment.
A secondary analysis involves identifying the services opportunities and partnership possibilities in your area. A stakeholder analysis of the key service organizations, their scope, reach, and activities can lay the foundation for developing a constructive partnership, with mutually defined responsibilities. Finally, the need for social support services for TB patients requires a great deal more advocacy and attention at the highest level, to ideally lead to an integrated policy framework to ensure that all TB patients are able to access the comprehensive range of assistance they need. Opportunities to participate in this advocacy and to promote dialogue and sharing of lessons on how to effectively organize support networks should be sought whenever possible.

**Figure 9: Framework to identifying Patient's support needs**

- I. Need assessment
  - Legislation of Social Protection schemes
  - Broad involvement of national bodies for sustainability of SS services

- II. Stakeholder analysis
  - Organization description
  - Potential role
  - Level of commitment
  - Available resources
  - Constraints

- III. Developing collaborative partnerships
  - Identifying gaps in existing SS services
  - Identifying vulnerable groups
  - Setting up referral procedures
  - Maintenance of relationships & follow up
  - Adressing existing gaps

- IV. Partnership advocacy
  - Statement of common goals and activities
  - Existing Social Support (SS) Services
  - Existing laws, legislation on Social Protection for TB patients
  - Identifying vulnerable groups
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The *USAID TB CARE II Project* (2010-2015) is a five-year cooperative agreement implemented by a wide consortium of health and development organizations and led by URC. TB CARE II is designed to provide both global leadership and targeted technical assistance on the ground to high burden TB countries. Through field support mechanisms, TB CARE II is assisting countries such as Bangladesh and Malawi in TB control efforts to support and expand DOTS, build coordinated systems for TB/HIV care and treatment, improve programmatic management of drug-resistant TB, and strengthen the health system for TB control. The project also implements global and regional activities designed to close critical technical resource gaps and provide leadership to scale-up proven strategies (www.tbcare2.org).