

เจริญวัยในนิคมโรคเรื้อนในรัฐมิลนาดู, อินเดียใต้



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GROWING UP IN A LEPROSY COLONY IN TAMIL NADU, SOUTH INDIA



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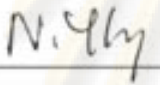
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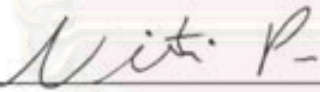
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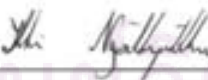
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อันนา สโวโปดา: เจริญวัยในนิคมโรคเรื้อนในรัฐทมิลนาฑู, อินเดียใต้ (GROWING UP IN
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ที่รัฐทมิลนาฑู ทางตอนใต้ของประเทศอินเดียขณะนี้ มีนิคมโรคเรื้อนอยู่ 42 แห่ง อัตรา
การลดลงของผู้ป่วยโรคเรื้อนในอินเดียไม่ได้เป็นผลมาจากการลดลงของจำนวนนิคมโรคเรื้อน
แต่สามารถดูได้จากการเปลี่ยนแปลงองค์ประกอบของประชากรในนิคมเหล่านี้ ปัจจุบัน ผู้ป่วย
โรคเรื้อนไม่ใช่ประชากรส่วนใหญ่ของนิคม ประชากรส่วนใหญ่คือลูกหลานของผู้ป่วยที่ปลอด
เชื้อโรคเรื้อน ดังนั้น ชีวิตในนิคมโรคเรื้อนจึงมิใช่ชีวิตที่เป็นพาหะของโรคเรื้อนอีกต่อไป

ใน 42 นิคมที่กระจายอยู่ทั่วทมิลนาฑู มีผู้คนอาศัยอยู่ 1,056 ครอบครัว และมีเด็ก 610
คน ในนิคมเหล่านี้ มีเด็กที่ป่วยเป็นโรคเรื้อนน้อยมาก เพราะการแพร่เชื้อในหมู่เด็กมีอัตราต่ำมาก
และเพราะตัวยาที่มีประสิทธิภาพในการรักษาสูง แต่ถึงแม้ว่ายาจะช่วยให้เด็กๆ รอดพ้นจากผลร้าย
ของโรค แต่มลทินอันเป็นผลมาจากโรคเรื้อนยังคงติดตัวเด็กเหล่านี้อยู่ การอยู่ร่วมกับพ่อแม่ หรือ
กับปู่ย่าตายายที่เป็นโรคเรื้อน ทำให้พวกเขาพลอยมีมลทิน และมีอัตลักษณ์ที่ต่างพร้อยไปด้วย
มลทินและอัตลักษณ์ที่ต่างพร้อยนี้กระทบกับมิติต่างๆ ของชีวิตเด็กๆ และหนึ่งในมิติเหล่านั้นก็คือ
การศึกษา

วิทยานิพนธ์นี้มีจุดมุ่งหมายเพื่อศึกษาชีวิตของเด็กๆ ที่เติบโตขึ้นมาในนิคมโรคเรื้อนในรัฐ
ทมิลนาฑู และเพื่อศึกษาผลกระทบจากมลทินของโรคเรื้อนที่มีต่อเด็กๆ ในด้านการศึกษา

ในอดีต เด็กที่เติบโตในนิคมโรคเรื้อนมักจะไม่ได้รับสิทธิในการศึกษา เด็กๆ ถูกปฏิเสธ
เพราะเขามาจากครอบครัวผู้ที่เป็นโรคเรื้อน แต่สถานการณ์กำลังเปลี่ยนไป เด็กๆ จากนิคมโรค
เรื้อนเริ่มเข้ารับการการศึกษา และมีส่วนร่วมในชีวิตในโรงเรียนมากขึ้น การที่เด็กเหล่านี้มีโอกาสเข้า
เรียนในสถานศึกษาดูเหมือนจะบ่งบอกว่าเด็กรุ่นใหม่ไม่ได้รับผลกระทบจากมลทินอันมาจากการ
เติบโตในนิคมโรคเรื้อนอีกแล้ว แต่วิทยานิพนธ์นี้แสดงให้เห็นว่ามลทินยังคงมีผลกระทบต่อ
เอกลักษณ์ของเด็ก และต่อความมั่นคงทางการศึกษาของพวกเขา

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ANA SVOBODA: GROWING UP IN A LEPROSY COLONY IN TAMIL
NADU, SOUTH INDIA

ADVISOR: SAIPIN SUPUTTAMONKOL. Ph.D., 100 pp.

Within the state of Tamil Nadu in Southern India, there are presently 42 active leprosy colonies. The decreasing rate of leprosy in India has not been trailed by a decline in leprosy colonies, but rather, an alteration in the demographic composition of the colonies has occurred. Leprous individuals no longer make up the dominant population of a colony with leprosy colonies now consisting largely of non-leprous children and grandchildren of the patients. Consequently, life in a leprosy colony no longer equates to being a carrier of the physical deformities of the disease.

In the 42 colonies spread throughout Tamil Nadu, there are 1056 families consisting of 610 children. Within these colonies, it is extremely rare to encounter a child who has leprosy due to the low rates of transmission among children and the high affectivity of MDT. Despite ridding this generation from the adverse medical impacts of the disease, the stigma of leprosy continues to follow the children. Through connection to a parent or grandparent suffering from the disease, children inherit a stigma of association and as a result experience a spoiling of identity. This spoiling of identity impacts them in various sectors of life, one of which is education.

This thesis intends to examine the lives of the children growing up in a leprosy colony in Tamil Nadu, as well as understand the stigma of leprosy as it impacts children in their access to education.

In the past, education has not always been a guaranteed right to children hailing from leprosy colonies, being denied largely based on their association to the disease. Yet, the situation is changing as children from colonies begin to access education and integrate into schools within society. The ability to secure education often implies that the present generation no longer suffers from the stigma of association. However, this thesis shows that stigma continues to taint the colony children's identity, influencing the way in which education is secured.

Field of Study: International Development Studies

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จุฬาลงกรณ์มหาวิทยาลัย

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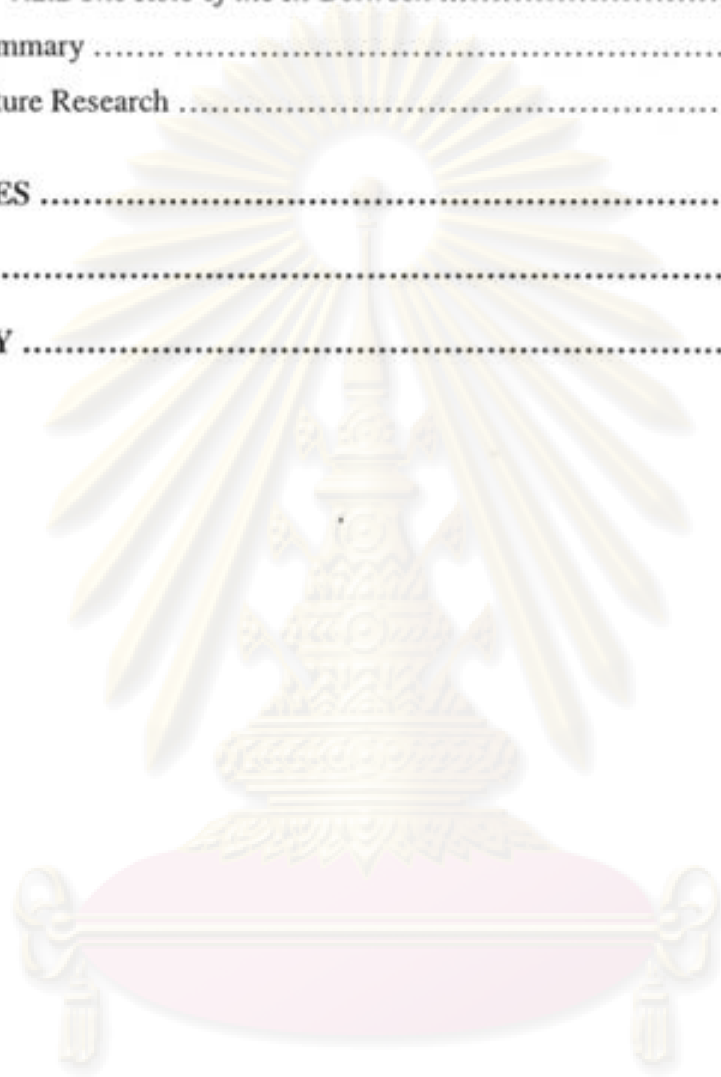
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ศูนย์วิทยทรัพยากร
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ABBREVIATIONS

IDEA India – Integration Dignity and Economic Advancement in India

HIV/AIDS – Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome

MDT – Multi Drug Therapy

NGO – Non-Governmental Organization

NLCP - National Leprosy Control Programme

NLEP - National Leprosy Eradication Programme

PR – Prevalence Rate

WHO – World Health Organization



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CHAPTER I

INTRODUCTION

My hands were gripped tightly around the seat as the rickety van overflowing with gauze, disinfectant and volunteers manoeuvred its way through unpaved, water logged roads in search of our destination, St. John's Leprosy Colony.¹ Out the window I watched women harvesting rice in the paddy fields pass by, until my attention shifted to the clump of mud huts coming into view in the distance. Inside the van the passengers began moving around gathering up medical supplies, alerting me that we were close to our destination. Approaching the colony gate, the driver slowed down, in an attempt to match the speed of the moving van with the colony children who ran alongside giggling and panting for air. The vehicle parked, and instantly the driver began blaring the van's horn to announce our arrival. Volunteers began constructing a basic medical station to serve the already-forming line of leprosy patients waiting for treatment under the mango tree. Unaware of the procedures, I helped where I could, but mostly played the role of an observer. After all, today was my first day of many volunteering with a local NGO working in leprosy colonies in Southern India.

As the day progressed, the line beneath the mango tree dwindled as leprosy patients made their way back to their homes having received temporary relief with their wounds cleaned and dressed. Ganapathi, an elder in the colony approached the volunteers for extra gauze and medicine to personally treat her particularly severe wounds as there would be no access to medical care until another NGO came through at the end of the week. While Ganapathi waited for the volunteers to pack the medical supplies, nearby, five year old Iswariya leapt up from her game of marbles to eagerly volunteer to carry the supplies for her grandmother. As Iswariya skipped away with the bundle of supplies tucked safely under her arm, I looked around at the colony that was to be my work place for a year. Children played with strips of unused gauze as

¹ St. John's Leprosy Colony is located in village of Venkatapuram in Kancheepuram district in the southern Indian state of Tamil Nadu. St. John's was a leprosy colony that I worked in with a social work organization from 2006 - 2007.

mothers aimlessly scolded them while they sat under the mango tree seeking refuge from the merciless Indian sun. Nearby, the noisy chatter of the male elders was hushed as a woman in a brightly coloured saree offered them tea to soothe the afternoon heat that had descended upon the colony.

St. John's Leprosy Colony was comprised of an assortment of young, old, leprous, and healthy. Living in the confines of a leprosy colony didn't necessarily equate to being a carrier of the disease. However, from my initial observations, life in the leprosy colony did seem to equate to a life lived in segregation from the broader society. Segregation didn't appear to be solely based on the visible presence of leprosy, but rather, isolation also came to those who were associated to carriers of the disease. This was to be the beginning of my introduction to the struggles, joys, and pains in the lives of individuals living within the confines of a leprosy colony.



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1.1 India and the Leprosy Burden

The disease of leprosy has troubled India for over 3000 years (Amnesty International, 2008) forcing the country to carry both the medical and social challenges of this perplexing and decimating disease. While today medical advancements have delivered a cure for the disease, a remedy to alleviate the social dimensions of the disease is yet to be found. Leprosy remains an ancient disease bearing a modern stigma that continues to instil fear in the minds of people.

This thesis will focus on the social aspects of the disease. However, to appreciate the social implications of leprosy a basic medical understanding is required. In this chapter we will consider the medical and social relationship that India, the country of research, has with the disease; secondly, a historical global overview of the medical and social aspects of the disease will be given; and lastly, a brief account of the recent history of leprosy in India will be considered.

1.1.1 The Medical Burden in India

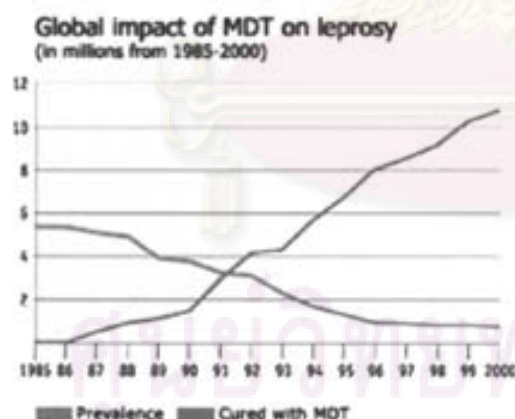


Table 1: Global Impact of MDT

abandoned, shunned, and forced to live as social outcasts. Various cures have been tested and tried throughout history, appearing momentarily hopeful, but failing shortly after. However, in the early 1980's, the leprosy prognosis underwent a momentous transformation as multi drug therapy, or MDT, was discovered (World Health

Leprosy is one of the oldest and most dreaded diseases in the world. For much of its history, there has been no effective medication to cure this disease which leaves its sufferers with dreadful deformities. Leprosy has been thought to be highly communicable, generating fear in a society that has left its sufferers

Organization, 2006). MDT proved to be highly effective and consumption of this cocktail drug containing rifampicin, clofazimine, and dapsone rendered the patient cured from infection (World Health Organization, 1995: 30–36). The revolutionary medical breakthrough of MDT was so dramatic that the World Health Organization, or WHO, implemented goals to reduce the global prevalence of leprosy to one case per 10,000 by the year 2000 (Fine, 2007: 2). As MDT became increasingly available in the 1980's, a dramatic shift was noted as leprosy endemic regions of the world experienced a sharp decline in the prevalence rate (PR) of the disease. Since 1995, the WHO has provided MDT free of cost to all endemic countries on a global scale changing the face of this once progressively debilitating and incurable disease. WHO states that, "the [global] prevalence rate of the disease has dropped by 90% – from 21.1 per 10,000 inhabitants to less than 1 per 10,000 inhabitants in 2000" (World Health Organization, 2008).

Despite the existence of a two-decade-old cure, leprosy continues to occur in large numbers within 24 countries in Asia, Africa and Latin America. The uneven distribution of the disease leaves the region of Southeast Asia carrying the brunt of the leprosy burden. Within this region, India accounts for 53% of all leprosy cases worldwide (World Health Organization, 2006). India has sought to amend its association with the disease with efforts dating to the pre-MDT era. In 1955, the National Leprosy Control Program, or NLCP, was created by the Indian Government in an effort to strengthen surveillance of the disease. With the discovery of MDT in 1981 the NLCP shifted its efforts from surveillance to an eradication approach. In 1983, the NLCP became known as the National Leprosy Eradication Programme, or NLEP, strengthening their commitment to provide MDT free of cost to patients throughout India. During this period, the case load of leprosy sufferers was considerably high with approximately "4 million suffers in the country" (Porichha, 2001: 32).

In 1995, the recorded PR of leprosy began to drastically decline as access to MDT became available free of cost in India (World Health Organization, 2006). Madhavan et al. (2007: 354) noted that in 1997, the Indian Government increased it

efforts by introducing leprosy elimination campaigns that focused on detecting leprosy cases, addressing training of village-level workers, and spreading awareness through media and community meetings. However, despite these efforts, India fell short of achieving the WHO's goal of leprosy elimination by 2000 with the PR hovering above one per 10,000 cases (NLEP, 2008). In response to this failure, the Central Government of India set out to implement a more rigorous strategy to achieve the WHO's goals. With the government's strengthened efforts, India continued to inch towards elimination of the disease with the 2001 PR standing at 3.1 per 10,000 cases (The Hindu, 2006).

In 2005, in accordance with the WHO's definition of elimination, India announced that the country had eliminated leprosy as a public health problem. However, in a country whose population exceeds one billion, the achievement of reducing the leprosy burden to one case per 10,000 loses its grandeur. In 2007 – 2008 the total number of leprosy cases in India stood at 83,000, marking the overall PR at 0.72 leprosy cases per 10,000, a sharp contrast to the PR of 62.4 per 10,000 cases in 1981 (The Hindu, 2006). The profile of leprosy has dramatically changed over the past two decades and India continues to be praised for its efforts to eliminate the disease. Complete eradication of leprosy however remains a daunting task to undertake.

1.1.2 The Social Burden in India

India finds itself facing not only the medical challenges of leprosy, but also the prejudices tied to the disease. This multifaceted disease possesses medical, public health, and social components. India has been commended for its efforts to address the medical and public health aspects of the disease, yet the social component of fear and shame associated with leprosy linger on as the pernicious aspects of the disease remain largely unaddressed. The social stigma of leprosy is largely rooted in the visible deformities carried by the sufferers. Throughout time, society has equated its deformities to infectivity, thus resulting in practices/acts to shield the public from the

disease. Dongre (2001: 14-15) lays out several of the practices/acts previously upheld pertaining to leprosy patients in India:

1. The Indian Railway Act – leprosy individuals were not allowed to travel with other passengers
2. The Motor Vehicle Act – leprosy individuals were not allowed to acquire a driving licence
3. Election Act – leprosy individuals were not allowed to contest any election
4. Separate Crematoria – deceased leprosy individuals must be disposed of in a separate crematoria
5. Disqualification of children of leprosy patients from schools – refusal of school admission to children from leprosy colony
6. Admission in General Hospitals – leprosy individuals were banned from being nursed in government hospitals

Over time, these practices/acts were legally repealed with the introduction of MDT and the increasing awareness of the disease (Dongre 2001: 14). Yet, despite the growing awareness of the disease, many continue to hold fearful views of leprosy individuals and practices, legal or not, continue to keep the sufferers separated and socially stigmatized.

The rate of new case detection in India is at an all time low due to the advancement in early case detection and the free accessibility of MDT (NLEP, 2008). Despite this, isolation of leprosy sufferers and their families continues, with over 1,000 active leprosy colonies functioning in India today (Walsh, 2007). These colonies, originally constructed to isolate the sufferers, contain a portion of leprosy patients. However, the majority of colony members now consist of children and grandchildren of the sufferers who at large, are leprosy free. The leprosy free individuals, one to two generations removed from the disease, remain within the confines of the colony to care for the elderly patients. These colonies provide its members with a place of belonging, solidarity, and refuge from the broader society. Nevertheless, this refuge comes at the cost of social exclusion. It is an exclusion

that has historically barred leprosy patients and their families from public functions, education, jobs, and access to basic services. Thus, the stigma of leprosy threatens to be a far greater battle to tackle as the attitudes and beliefs embedded in India's long standing history with leprosy must be addressed.

1.2 Global Medical History

1.2.1 A Medical Understanding

Leprosy, caused by the bacteria, *Mycobacterium leprae* is a unique disease. The bacterium primarily attacks the skin, immune system, and respiratory tract. There are three main modes of assumed transmission: "inoculation, or entry through broken skin; respiratory, breathing in the welter of germs known to be discharged from the nose of leprosy sufferers; or ingestive, through the gastrointestinal tract" (Gould, 2005: 13). Yet the exact mechanism of the bacillus transmission remains unknown. According to the WHO (2008), what is known is that the disease is only able to spread through close contact with an infected patient and only then, after prolonged exposure and a five to ten year incubation period. Further, leprosy is not highly contagious with approximately ninety-five percent of humans having a natural inbuilt immunity to the disease (American Leprosy Mission, 2008). Leprosy initially surfaces as pale patches of skin on the body. As the disease progresses, inflammation, paralysis and loss of feeling are experienced as a result of nerve damage (WHO, 2005). Brand (1993: 94) found that the destruction of nerve endings caused by the body's response to bacterial invasion leads to the loss of sensation, causing the sufferers to be highly prone to injuring themselves and losing limbs. Leprosy's adverse effects are dual: breaking down the internal immune system while the outward ligaments painlessly rot away.

Up until the late nineteenth century, little was known about the disease and treatment relied primarily on assumptions reinforced by religious, cultural and folk beliefs of the time. In 1870, however, a medical breakthrough was on the verge of being made through the work of Norwegian physician, Armauer Hansen. Dr. Hansen,

going against the grain of popular belief, was sceptical and challenged the widely accepted idea that leprosy was heredity or caused by miasma.² His studies led him to propose that leprosy was a specific disease with a specific cause. In stating this claim, the doors for controversy with his medical superiors were flung open. Hansen's hypothesis proposed that a bacterium was the transfer agent of the disease. In 1873, at the age of 32, Dr. Hansen was the first to identify the rod-shaped bacteria present inside the cells as *Mycobacterium leprae* (Watts, 1997), the bacteria responsible for carrying and transmitting the disease. This discovery was the first stepping stone in addressing misconceptions and constructing a more accurate medical understanding of the disease.

1.2.2 Treatment

Despite the medical advancements, an effective cure was yet to be found to treat patients and break the chain of transmission. Up until 1940, medical practitioners relied on treating leprosy by injecting patients with oil from the chaulmoogra nut.³ Although chaulmoogra oil cured a handful of patients, it was painful and a questionable method of treatment (Gould, 2005: 18-19). Promine, the sulfone drug, was introduced in 1941 as a potential cure for leprosy. Seemingly hopeful, promine secured higher success rates than chaulmoogra oil, yet the numerous painful injections made it inconvenient and eventually, a failed attempt. The 1950's brought with it treatment in the form of a dapsone pill, which gained in popularity, but not long after the pill was introduced, *M. leprae* outsmarted the drug and responded by building up a resistance to dapsone. However, after much trial and error, a drug combination being tested on the island of Malta in the 1970s was introduced, claiming to be highly effective. This drug combination of rifampicin, clofazimine and dapsone became known as multi drug therapy. After scrutiny and examination, in 1981, the WHO publically recommended MDT as an effective combination of drugs to treat

² Miasma, a vaporous exhalation formerly believed to cause disease

³ The oil from the nut produced by the chaulmoogra tree has traditionally been used for thousands of years in the treatment of leprosy

leprosy (American Leprosy Mission, 2008). This recommendation proved to be a revolutionary step in addressing the disease.

1.2 Global Social History

The mysterious malady of leprosy has had wide reaching impacts. Geographically, the disease has known few limitations, with cases spanning from the Americas, through Europe, Africa, Asia, and into the Pacific (Whitcher, 2000: 809). While each region affected has handled the disease differently, banishment and removing the presence of the disease carriers from society has been the unifying practice among those untouched by the disease.

1.3.1 Religious Interpretation of Leprosy

Leprosy has been a widely misunderstood disease with skewed perceptions based on limited medical knowledge, coupled with the fear of contagion. Throughout history, leprosy has been perceived as a moral condition. This was condoned through various religious texts. Two notable religious texts referring to this disease are the Christian *Holy Bible* and the Hindu *Laws of Manu*. The *Bible* goes into detail describing the instructions God gave to Moses stating that, "...the leper in whom the plague is, his clothes shall be rent, and his head bare, and he shall put a covering upon his upper lip, and shall cry, Unclean, unclean" (Lev13:35 KJV). The *Laws of Manu*, in the Hindu text dating back to 1500 BC, contained instructions on the manner of dealing with those inflicted with the disease. According to Buhler (1886), this standard book of the Hindu canons laid out rules that prohibit interaction with leprosy individuals as the disease was said to stem directly from sinful acts of the carrier. Both texts played a pivotal role in shaping and justifying society's treatment of leprosy sufferers.

Reinforced by religious beliefs, leprosy was seen as a repercussion of one's moral character. Actions taken against leprosy patients were deemed acceptable by various religions. In Indian Hinduism, the act of suicide was condemned and labelled

as a solemn sin. Yet, for leprosy sufferers, suicide was not only acceptable, but encouraged by Hindu priests. Written accounts by Europeans residing in India documented encounters with acts of ritual suicide being committed by leprous individuals (Campbell, 1869: 195-196). Society's repulsion of the leprous individual ostracized him from society, which in turn, led to distain and rejection of self. Marked with physical deformities and shunned by society, leprosy victims became recipients of the curse society cast upon them.

Historically, fear and misunderstanding of the disease has led to forced segregation. Fear associated with the disease began to spread across Europe during the Middle Ages. The fear of contagion resulted in inflicting punishment on those marked with the disease, shunning them from society, ushering the sufferers into forced starvation and immolation (Browne, 1985). A public appearance of a leprous sufferer required them to mark and identify themselves by wearing white capes and warning bells (Gould, 2005: 5). Suspicion of leprosy in the community would result in sending the suspect to a local priest for inspection. If upon inspection the person was announced as being leprous, a formal service, or Lepers Mass would be conducted. This service condemned the leprous sufferer as dead and segregated him/her from the community (Brand, 1993: 319). During this era, the church upheld the Lepers Mass as a part of defending the good of the wider community. At the turn of the seventeenth century, leprosy reached the shores of Holland presumably carried over from the tropics via the commercial spice trade. Throughout Holland, carriers of leprosy were forced to report to The Hague for verification of the disease. Rieser (2000: 130) found that, "all their worldly goods [were] confiscated, they had to wear a white head band and they and their families had to rely on alms as penitent sinners." Leprous individuals were condemned to segregated colonies and "their only reward for penance was rehabilitation in heaven."

1.3.2 Social Isolation

The curse coupled with fear affixed to the disease led to the isolation of leprosy patients through the construction of leprosy colonies. Traditionally, leprosy colonies were set up to exclude the infected from society in order to prevent wide spread contagion. Colonies were traditionally constructed through government policies, however, Christians and Catholics played an instrumental role in caring for leprosy patients by setting up institutions and leprosy homes (Hardiman, 2006). The practice of quarantining off leprosy patients presumably dates back to the twelfth century. The Order of Saint Lazarus, one of the oldest recorded establishments formed to accommodate leprosy individuals during the period of the Crusades is one example. Lazarus, the leper accounted for in the Bible was represented as the patron saint for those who suffered from leprosy and thus the formation of the Order of Saint Lazarus in Jerusalem. This order was established to care for and aid leprosy victims who had been shunned from society (Marcombe, 2004: 3-4).

The politics of segregation was the topic of the First International Leprosy Conference in 1897 in Berlin. Jules Goldschmidt, the superintendent of the leprosy asylum in the Portuguese island of Madeira stated that, "it was essential...that all lepers and their families, if not confined within leprosy hospitals, should yet be restricted to their villages and be denied opportunities for social intercourse with the public at large" (Pandya, 2003). The conference endorsed that segregation would reduce the spread of the disease. As a result, other countries began to execute laws for addressing contagion through confinement.

Accounts of India's management of the disease date back to the period of British Rule in India.⁴ Henry Vandyke Carter, an Englishman and one-time Deputy Surgeon General of the Indian Medical Service, was a notable expert on leprosy. He campaigned for the control of leprosy in India through "legal and institutional measures" (National Library of Scotland, 2007). Carter's recommendation for social isolation of leprosy sufferers stemmed from the leprosy asylums he witnessed in

⁴ The British Raj established its rule in India between 1858 to 1947

Norway. At the time, the leprosy causing bacillus had been discovered, yet the belief that the disease was hereditary, highly contagious, and unable to be cured persisted. Consequently, Carter pushed for a confinement of leprosy sufferers from the broader Indian society and a segregation of the sexes to eliminate reproduction (National Library of Scotland, 2007).

1.4 India History of Leprosy

The isolation of leprosy individuals in India dates back to ancient times. However, direct legal measures to ostracize the affected were introduced under the British Rule in the late 1800's. During British Rule in India leprosy was seen through both medical and religious lenses. In the Hindu *śāstric*⁵ leprosy was defined as a condition "entailing profound ritual pollution, a state which had considerable implications for the sufferer's relationships with family and community" (Hardiman, 2006: 24). Once labelled as leprosy, one's ritual and social identity was stripped away. Even so, "*śāstric* tradition did not neglect the outcast sufferer completely, but required that the family provide maintenance for their physical support" (Hardiman, 2006: 26). Despite the restrictions against sufferers noted in the *śāstric*, aversion of leprosy patients appeared to be far greater among Europeans.

Buckingham (2002: 42) notes the levels of aversion towards leprosy within the native Indian population was less severe. This is disputable though when leprosy is considered in regards to class as individuals afflicted by poverty and leprosy were viewed with distain and horror among the Indian population. Willock observes that: "the unfortunate victims whom we see begging about the streets . . . are shunned and avoided by everyone" (2002). Leprosy in India is forged to the history of the poor. The poor leprosy beggars in India were prime targets and became "recipients of British institutional care, the test cases for new leprosy treatments and the targets of confinement" (Buckingham, 2002: 37). Further, through the lens of Hinduism, it was not the financial stable, but poor leprosy sufferers that were prone to social and

⁵ The word *śāstric* refers to the Hindu branch of analytical and intellectual reasoning. Instead of being schooled under a single teacher, the *śāstri's* are generally taught in a school.

religious banishment. Cursed with the disease and trapped in poverty, leprosy individuals were ostracized from society.

In 1889 India passed the Lepers Act containing laws that exemplified the beliefs and attitudes of the day. The Lepers Act implemented in 1889 was a Bill to make provision for the isolation of lepers and the amelioration of their condition. Under the Act, the leprosy hospital was, in effect, a prison for beggars suffering from leprosy. "In targeting paupers with leprosy for forced confinement, the Bill was clearly in agreement with Indian class feeling." Further the Europeans, who bought into Foucault's understanding,⁶ saw the vagrant leprosy sufferer as rightfully belonging in confinement as the "wall of the asylum was a true home for them" (Buckingham, 2002: 42). In a single swipe, the leprosy paupers that planted fear in Europeans and were looked down upon amongst Indians were conveniently banished from society under the Lepers Act. One can pose the question asking if the Act sought to control the disease or criminalize the pauper?

At the start of the twentieth century, the government found itself standing at a crossroads and evaluating the current situation. The realization that the measures that had been used to implement the Lepers Act nationwide resulted in being ineffective. Buckingham states that, "apart from satisfying the moral demands of imperial care for British subjects and providing a forum in which the Indian upper-middle class could express their solidarity with the values of the educated rulers, the Lepers Act did little for the colonial cause." Thus came the transfer of leprosy care, entrusting the bulk of the work over to the Mission to Lepers. The Mission to Lepers, a Protestant mission founded in 1874, aimed to aid those "suffering from leprosy and from its social consequences by giving financial support and general guidance" (Buckingham, 2002: 75 - 79). This was an unexpected transfer, handing responsibility from a government to a missionary approach, which occurred at a time when, "missionaries were increasingly perceived in India as an extension of the empire and as supporters of colonial rule against the forces of nationalism." With leprosy sufferers under

⁶ Since the publication of Foucault's *Madness and Civilization* (1961) and *Discipline and Punish* (1975), leprosy, poverty, criminality and insanity have tended to be understood less as discrete conditions and more as characteristics which unite those living 'in the margins of the community' and mark them out for exclusion

missionary care, their physical, emotional and spiritual needs were tended to. Miller (1999: 14) writes that, “the total man called for total-help in his total need.” This transfer marked not only a change in roles, but a change to the current face and future of leprosy patients.

1.4.1 India: A Country in Transition

With the introduction of MDT in the 1990’s the leprosy situation has radically changed as vertical programmes have been discarded, physical rehabilitation of patients are in place, advocacy initiatives on the rise, and social and economic rehabilitation programmes are being constructed. With the medical burden of leprosy decreasing, the scene for leprosy workers is dramatically changing. Now, more than ever there is a need to address the social, economic, and psychological impacts connected to the disease. Advocacy initiatives and leprosy awareness campaigns have aided in the gradual shift being seen within India, a country that has marginalize and isolated leprosy sufferers and their families for centuries. However, as stated, this shift is gradual, and appears to be a shift that is presently occurring in expressed perceptions of society, but yet to materialize in reality. Nearly all sufferers and their families continue to live isolated from society and trapped within the limitations of stigma.

ศูนย์วิทยทรัพยากร
จุฬาลงกรณ์มหาวิทยาลัย

CHAPTER II

PROBLEM STATEMENT/BACKGROUND

The harmful impacts of leprosy reach beyond those who suffer from the physical deformities of the disease. The stigma associated with the disease impacts the sufferers, spouses, offspring, and generations that follow. Children, free of the disease, grow up within the confines of the colony and as a result, are denied the freedom to freely participate in society. Historically, children from leprosy colonies have lacked the guarantee of securing education. This lack of access has been due to various factors, including:

1. The inability to secure school admission for children from leprosy colonies
2. The inability to continue education due to the deterioration of physical deformities
3. The lack of economic stability to enroll colony children within school

Today, thanks to MDT, children in leprosy colonies are healthy, thus eliminating the obstacles previously created by deformities. India's commitment to 'Education for All' still stands today as it has for over 50 years. However, despite a generation of virtually leprosy free children and a legal commitment to education for all, obstacles in obtaining education for children from leprosy colonies are reported.

This chapter will discuss the situation children living in leprosy colonies find themselves in, specifically in regards to their access to education. Additionally, this chapter will discuss the research's aims and objectives.

2.1 Background

2.1.1 Tamil Nadu, South India

In 1997, the southern state of Tamil Nadu became the first state in India to achieve the WHO's benchmark of leprosy elimination. This was a notable achievement, considering that Tamil Nadu was once home to 800,000 patients, the highest concentration of leprosy patients in India. Today in 2008, the PR has been reduced to less than 0.53 per 10,000 in Tamil Nadu (Varma, 2008), a rate that Tamilian leprosy workers can be proud of in light of the national PR currently standing at 0.72 (NLEP, 2008).

Tamil Nadu has evidently addressed the medical aspects of the disease, yet the harmful social aspects remain. The stigma of leprosy continues to be a phenomenon in the lives of individuals, impacting them socially, physically, psychologically, and economically, as well as marginalizing leprosy sufferers and their families. Within the state of Tamil Nadu there are presently 42 active leprosy colonies out of the 1000 registered colonies in India (Gopal, 2001: 44). The declining rate of leprosy in India has not led to a decrease in colonies, but rather, to an alteration in the demographic composition of a colony. Consequently, life in a leprosy colony no longer equates to being a carrier of the disease. According to Gopal (2001: 45):

In the past, the number of affected people living in a colony was very high. Nowadays the number of leprosy affected individuals is less and those who have the disease are aged... the population within the colony represents more of a normal population than not.

In the 42 colonies spread across Tamil Nadu, there are 1056 families consisting of 610 children (Gopal, 2001: 44). Within these colonies, it is extremely rare to encounter a child who is a carrier of the disease due to the low rates of transmission among children and the high affectivity and available MDT. The present generation of children have been shielded from the adverse medical effects of the

disease yet remain exposed to elements of the social burden. Children in the colonies represent a unique case as they are intimately connected to a family member with the disease, yet able to integrate into society to an extent unknown to past generations. Nevertheless, children grow up encountering limitations based on where they live and who they are associated with.

2.1.2 Education in India

Education plays a fundamental role in the development and opportunities of a society, equipping individuals with the tools needed to survive and succeed in life. Since the framing of the Constitution in 1950, India has upheld a commitment to Education for All. India has worked to uphold a policy of equality, documented in clause 2 of Act 25 in the Indian Constitution stating that: “No citizen shall be denied admission into any educational institution maintained by the State or receiving aid from out of State funds on grounds of religion, race, caste, or language” (Government of India, 1950). Further, educational policies designed to support the marginalized sectors of society have been implemented. Galanter (1986: 375) states that Article 46 of the Constitution includes the ‘Directive Principle of State Policy’ which declares: “The State shall promote with special care the educational and economic interests of the weaker sections of the people...and shall protect them from social injustice and all forms of exploitation.” However, despite the noteworthy constitutional decrees, India’s attempts to establish an egalitarian educational order has proved to be challenging as caste, class, and social order present complications in this noble quest with each component being deeply ingrained into the construction of Indian society.

Today, discrepancies exist between the written claims of the Constitution and reality. As a result, new bills continue to be drafted in an attempt to guarantee education for all of India’s children. Most recently, in 2005 the country witnessed the introduction of a new bill known as: The Right to Education. “Broadly speaking, it aims at setting minimum standards for both public and private schools so that the quality of education improves throughout the country and the current inequities are

levelled” (Mukherji, 2008: A2). The overarching aims of this bill are commendable, yet controversy has surfaced in the route proposed to achieve these aims. In the task to level the playing field, the hotly debated clause makes it compulsory for all “private schools to reserve 25% of their seats for poor children from the neighbourhood” (Mukherji, 2008: A2). This bill is yet to be passed as of 2008, and various amendments have been composed to push for an acceptance of the bill.⁷ Since independence, “India had undergone what might crudely be summarized as development at the upper end and stagnation at the bottom” (Galanter, 1986: 82). Progress has been made, but the social stigmatization attached to caste, economic standing, and class continues to leave many excluded.

2.1.2.1 Children from Leprosy Colonies: the Link

In the past, the Persons with Disabilities Act (Disability India Network, 1995) could be referred to in order to assess the legal rights that leprosy children have in regards to education. However, today we are confronted with a different predicament as it is rare to encounter a child in a leprosy colony that is a carrier of the disease. Despite ridding this generation of children from the adverse medical impacts of the disease, the social burden of stigma continues to be lumped upon them. The stigma that is imposed upon the children impacts the opportunities they have to access various social services, one of which is education. However, stigma cannot be assumed to be the sole barrier present in accessing education, and the other limiting factors that children from leprosy colonies might face in their attempt to access education must also be examined.

Once labelled as leprous, society robs the sufferer of his identity and dignity and all that was once possessed is lost. Further, once leprous, one's identity becomes

⁷ Besides the controversy that undermines the bill, there are other barriers, one of which is the staggering cost of implementing such a bill. However, Nilesh Mimkar, an advisor of UNICEF Maharashtra, India states that, “Without education it is virtually impossible to lead a life of dignity. It's important for the government, within reasonable limits, spend on education.” His word carries weight, especially when considering that India spends approximately “3.7% of its GDP on education.” This is meagre amount when comparing the statistic to the 6% of nations GDP that is reserved for education in countries that ‘put a premium on education.’

branded to being a social outcast, an untouchable. One's association to the disease becomes the identifying factor, taking precedence over the identity that caste previously provided. Subsequently, children of leprosy individuals are born into the 'outcast' status that their parents have inherited. This, in my reasoning, presents the first obstacle that children from leprosy colonies might encounter in their attempt to access education – they are social outcasts and therefore experience hardships in securing education.

Secondly, leprosy colonies have historically existed on the fringes of society, established in rural settings, secluded from the larger society. This is not to suggest the absence of urban colonies; however, colonies in rural settings are the overwhelming norm. Being situated in rural India limits access to public services made widely available in more metropolitan settings. Further the quality and standard of these services do not always mirror that of their urban counterparts. Schools in rural India exist, however "on an average, an upper primary school is 3 km away in 22 percent of the habitations" (Swati, 2008). Therefore, securing education could become an obstacle due to the physical accessibility of schools.

Thirdly, since universal free education is yet to be implemented throughout the country, education generally comes at a cost. No matter the cost, relatively large or small, there is a cost involved. For children from leprosy backgrounds, the knowledge of the cost that precedes obtaining an education could serve as a barrier due to the economically depressed circumstances represented in most colonies. Because of these economic circumstances, education may be considered as a luxury and the hotly debated topic of the perceived value of education among the poor becomes another component as to why an education is not secured.

The above reveals that stigma is not the exclusive factor that might bar colony children's access to education. The combination of the above factors pose very real concerns and a child's basic right to education is at stake if they cannot overcome the hurdles presented by caste/class, physical access to schools, and economic circumstances. However, if one can rise above these hurdles, this in itself

does not guarantee them securing an education. After successfully bypassing the discussed barriers, children from the colonies may find themselves denied the right to education based on the barrier presented by stigma. One must question if India's Constitutional commitment to Education for All has the ability to pierce through the barriers and provide for those at the bottom of the social ladder. If access to education was made available and was an assumed right for all children, a marked difference could be made in the outlook and future of these children's lives.

2.2 Hypothesis

This thesis will propose the following:

Despite the advancement of medical knowledge and treatment, leprosy remains a disease that still strikes and conjures up fear in society. Leprosy itself has become a metaphor for stigma. The stigma associated with the disease impacts those who carry physical deformities but also, impacts individuals who are related and associated to a leprosy person.

This thesis intends to examine the lives of the children growing up in a leprosy colony in Tamil Nadu, as well as understand the stigma of leprosy as it impacts children in their access to education.

In the past, education has not always been a guaranteed right to children from leprosy colonies, being denied largely based on their association to the disease. Yet, the situation is changing as children from colonies begin to access education and integrate into schools within society. The growing ability to secure education often implies that the present generation no longer suffers from the stigma of association. However, the process by which education is secured should be considered and if barriers pertaining to stigma exist.

2.3 Research Questions

1. What is the current situation of access to education for children growing up in leprosy colonies?
2. How does the social stigma attached to the disease impact access to education for children from leprosy colonies?
3. If education is accessible, does it have the ability to provide children with a different outlook to that which has been experienced for generations within the colony?

2.4 Objectives

1. To consider the living conditions of children living in the leprosy colony
2. To identify barriers that exist in regards to securing education
3. To evaluate if education is a vehicle that can lead to a life lived beyond the limitations of stigma.

2.5 Significance of Study

With the 2006 global registered rate of leprosy standing at 219,826 cases (WHO, 2004), it can be affirmed that leprosy is not a disease of the past.

WHO Region	Registered prevalence* (rate per 10,000 population) 2005	New cases in 2005 (rate per 100,000 population)
Africa	43,425 (0.63)	44,769 (6.48)
Americas	32,910 (0.39)	41,952 (5.00)
South-East Asia	133,422 (0.79)	201,635 (11.99)
Eastern Mediterranean	4,024 (0.08)	3,133 (0.61)
Western Pacific	8,646 (0.05)	7,137 (0.42)
Total:	222,427	298,626

Table 2: Global Registered Rate of Leprosy.

*Rates of prevalence and new case detection (shown in parenthesis) were calculated based on population data for the year 2005 from United Nations Population Division (WHO, 2004).

Leprosy continues to impact sufferers and their families with colony children being the unobvious sufferers in the scenario. Children have been overlooked as the majority have escaped the visible medical burden of the disease. However, there is a need to focus attention on children who fall victim to the stigma associated with the disease as they are the hope and future of the colony.

The findings of this thesis will build on the present understanding of the situation that exists for children living in leprosy colonies. The research will be a contribution to the academic community, providing insight into the complexity of the dilemmas associated with growing up in a leprosy colony. In doing so, this thesis establishes the potential to serve as a practical application to assist individuals and organizations working within leprosy colonies. The findings of this thesis will aid in the process of identifying the struggles and barriers faced by children within the colony.

2.7 Ethical Considerations

In carrying out this research, participants were notified of the broad aims and purposes of the research. Verbal consent was secured from each participant before actively involving them in the research. In the interviews conducted with children at Gnanodaya School, verbal and written consent was secured from the school's headmaster who also serves as a guardian for the children. Several interviews were conducted in which informants disclosed potentially controversial information under the knowledge that their identity would be masked. Further, in the case of the school children and colony members, fictitious names have been used to mask their real identities. All the participants were aware that the research carried out was for academic purposes.

2.8 Scope of Study

The scope of this study will consider leprosy in India focusing specifically on children growing up in St. John's Leprosy Colony and their access to education. In considering access to education, I will seek to examine if the social stigma attached to the disease plays a role in obtaining education.

The focused scope of the study will lay within the perimeter of Tamil Nadu, specifically focusing on St. John Leprosy Colony in Venkatapuram, Kancheepuram district. In considering access to education, primary data will be gathered from informants in St. John's Colony, Gnanodaya School, and the local community of Venkatapuram and Singaperumalkoil. Secondary data will be obtained through NGO's and government organizations.

2.9 Limitations

Limitations arose from this study, most of which were a reflection of the restricted parameters of my research and due to the exceptional nature of my research site. In order to gain a more comprehensive understanding of children living in leprosy colonies there is a need to carry out research in a number of randomly selected colonies. Further, in-depth research should be carried out in local schools that have been reported to deny admission to children from leprosy colonies in the past. Attention should be drawn to the unique nature of my case study and the significant financial support from outside sources that was noted within St John's Leprosy Colony.

จุฬาลงกรณ์มหาวิทยาลัย

CHAPTER III

LITERATURE REVIEW

Leprosy has been defined by a pervasive stigma throughout history; with the very word evoking images of “grotesquely deformed” sufferers (Gould, 2005: 1). Within various regions of the world the stigma attached to leprosy has been accompanied by discrimination towards the sufferer. Throughout time fearful aversion projected towards leprous individuals has been translated into acts of discrimination and marginalization of the infected (Alonzo et al. 1995). As a result, discrimination has become the action arm of stigma.

This chapter will look at the concept of stigma and the significant academic work that has been compiled on the topic. This chapter will consider the gaps that exist within the literature and how it differs from the research of this study. Lastly, the conceptual framework that will be used in laying the foundations for this thesis will be introduced.

3.1 Defining Stigma

Stigma, from its original Greek root, refers to markings on the skin or a tattoo. “Ancient Greeks learned the technique from the Persians, and the ancients used to mark slaves, criminals, and prisoners of war for punitive purposes so they could be identified if they tried to escape” (Jones, 1987: 140). Yet, our interpretation and use of the word stigma has morphed through the years. “Although the initial connotation of intentionally scarring people to signal their disgrace remained, the term stigma has come to encompass marks, both seen and unseen, affixed by people or even the divine” (Smith, 2007: 463).

There is wide variability that exists in literature concerning the concept of stigma (Stafford & Scott, 1986: 80). The concept of stigma itself is used in various contexts with psychologist, medical scientist, anthropologist, social geographers,

sociologist and political scientists employing use of the concept (Link & Phelan, 2001: 365). Therefore, the definitions proposed vary and are filtered through the channels of the scholar's specific discipline and framed around a diversity of theoretical reference points. A standard and broad description of stigma can be drawn from the dictionary based definition that suggest that stigma is: "a mark of disgrace" (Collins Dictionary, 1984: 483). A range of definitions have been offered by scholars that propose stigma to be the following: "a characteristic of persons that is contrary to a norm of a social unit" (Stafford & Scott, 1986: 81) or a definition that gained popularity presented by Jones et al (1984) states that stigma can be considered as a "relationship that exist between an attribute and stereotype." Other definitions suggest that "stigmatized individuals possess (or are believed to possess) some attribute, or characteristic, that conveys a social identity that is devalued in a particular social context" (Crocker et al, 1998). According to Gilmore and Somerville (1994: 1340), stigma is an "attribute used to set the affected persons or groups apart from the normalized social order, and this separation implies devaluation." Further, stigma has been defined in the context in which discrimination is exerted based on moral judgements on why the individual inherited the stigma (Kegeles et al, 1989: 356). The concept of stigma and discrimination commonly appears side by side and according to Malcolm et al (1998: 350), the combination of the two can be viewed as an "enacted stigma."

A myriad of definitions exists due the complex nature of stigma and the framework it is interpreted through. However, there is a general overlap that occurs that illustrates regardless of the framework of the interpreter, stigma can be seen as a "negatively perceived defining characteristic" (Busza, 1999: 1). Furthermore, because stigma is not a static concept there is value in giving room for flexibility in seeking to definite stigma.

Studies and attempts to define and refine the concept of stigma largely stemmed from the work by Erving Goffman, a renowned sociologist who has been considered as the "founder of modern stigma theory" (Hopwood, 2007: 1). Goffman's most notable work on stigma is found in his book: *Stigma: Notes on the*

Management of Spoiled Identity (1963). In his work, Goffman focuses specifically on people with mental illness, physical deformities, and social deviant behaviours as he considers the interactions between individuals that lead to stigmatization. He described stigma as “an attribute that is deeply discrediting within a particular social interaction” and applies the term stigma to “any condition, attribute, trait, or behaviour that symbolically marks off the bearer as *culturally unacceptable* or inferior, with consequent feelings of shame, guilt and disgrace” (1963: 3). Goffman suggests that stigma doesn’t represent a specific attribute but rather an individual has been labelled as stigmatized due to the social meaning ascribed to the specific attribute. It is suggested that the person possessing this blemished attribute is thus reduced in our minds and “...we believe the person with the stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances” (Goffman, 1963: 5). Goffman proceeds to define the divergence that exists between an individual’s virtual and actual identity. “This discrepancy, when known about or apparent, spoils his social identity; it has the effect of cutting him off from society and from himself so that he stands a discredited person facing an un-accepting world” (Goffman, 1963: 19).

To simplify and condense Goffman’s work, we can divide this stigma of which he speaks into three basic categories:

1. Abominations of the body—*various physical deformities that included diseases such as leprosy*
2. Blemishes of individual character—*weak will, dishonesty*
3. Tribal Identity—*stigma associated with ‘tribal identity’ such as ethnicity and religion*

Regardless of the different categories of stigma that are experienced, the outcome of the stigmatized individual is that of a spoiled identity. A spoiled identity cast shame upon the individual and is sought to be managed through the act of concealment, defiance, and irony. Stigmatization in itself is society responding to what they have come to label as spoiled identity. Goffman (1963: 5) states that:

the attitudes we normal's have toward a person with a stigma, and the actions we take in regard to him, are well known, since these responses are what benevolent social action is designed to soften and ameliorate. By definition, of course we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances. We construct a stigma-theory, an ideology to explain his inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences, such as those of social class.

3.2 Stigma and Leprosy

Leprosy carries a high level of stigmatization (Goffman, 1963; Jones et al., 1988; Rafferty, 2005). Within the Indian context, society has often blamed leprosy sufferers for their condition, attributing the disease to a lack of hygiene; curse from God; sexual immorality; and the sins of their forefathers (Chaturvedi & Singh, 2005: 632). Despite leprosy being easily cured, there is a low level of understanding present among the public and leprosy population about the disease. Thus, the public is threatened by this fully curable, low communicable disease while the disease carriers often neglect seeking treatment in an attempt to conceal the disease out of fear and shame. Additionally, doctors and health care workers fall into the trap of stigma, in refusing to administer the free medication (MDT) out of fear of contagion. Eventually, the fear of both the public and the sufferer towards the disease results in the creation and perpetuation of stigma. Thus, in response to being labelled and devalued, individuals possessing this stigma become social outcast and are thrown out from their homes, jobs, communities and live within the confines of a colony.

3.3 The Influence of Stigma

Stigma is learned and passed down from generation to generation, by the perceptions held by outsiders and the stigma that is created through self-perception. Through stigma, labels, responsibilities, obligations, and markings are communicated. The communication of stigma then is the act of spreading a message that imparts to

society a public acceptance of fear and labelling which results in actions of discrimination and rejection. In a study carried out by Smith (2007: 463), stigma is said to bear the following attributes: "it provides cues (a) to distinguish people, (b) to categorize distinguished people as a separate social entity, (c) to imply a responsibility for receiving placement within this distinguished group and their associated peril, and (d) to link this distinguished group to physical and social peril. Different qualities of stigma messages, moreover, evoke different emotions (disgust, fear, and anger) that motivate people to access relevant social attitudes, form or bolster stigma attitudes, and to remove the stigmatized threat. Stigma attitudes encourage the sharing of stigma messages with others in a network, which may, subsequently, bond in-group members."

As illustrated in Smith's (2007) study, stigma marks, identifies, isolates, and lastly robs the sufferers of their humanity. These attributes of stigma ultimately result in "linking the group to both a physical and social peril." These different degrees and stages of stigma are connected and mutually dependant on one another. When an individual is belittled and dehumanized psychologically, violence against them has occurred. However this violence enacted against them merely is setting the stage for what is to follow. What follows can be labelled as real violence as this violence is what condemns those within leprosy colonies to a live a life that is unliveable as inflicting this violence upon them has removed them from society. When we refer to a liveable life it is useful to refer to Chambers (2007: 46) viewpoint that states that "the possibility of a *lived* life hinges on the notion of intelligibility, on the capacity to be recognized as a subject, an agent. A lived life is only possible as a recognizable subject, and this notion of recognisability/intelligibility might be thought through the idea of a "received" subject...being received makes one a subject; it makes a lived life possible." Considering Smith's study dealing with the attributes of stigma that results in ultimately condemning the targeted group to both a physical and social peril and connecting it with the notion that Chambers puts forth stating that life is only liveable when one's humanity is validated and for that to occur there must be a receiving of who they are and an acceptance of their humanity. This notion of acceptance and validation of one's humanity is the very thing that fails to happen for those who carry

the mark of leprosy and for those who are associated with leprosy patients. In society's failure to deem them as liveable a violence has been carried out and projected on them that condemns them to a life that is unliveable and further, it can be proposed that their lives become an invisible existence and their suffering itself is ungriveable as the stigma not only labels them with a social peril but upon labelling them, it condemns, isolates, and erases their very existence and place in society.

Individuals with leprosy are able to cope and live a good life despite their physical impairments. Yet, when a person is rejected, looked down upon, and alienated from society, life becomes meaningless. This is the power of stigma. There are two main forms of stigma – felt stigma which refers to “the shame associate with potentially stigmatizing condition and the fear of being discriminated against” (Link & Phelan, 2001) and enacted stigma which occurs when one experiences discrimination that stems from the stigma (Scambler, 1998: 1054 - 1055). The relationship between stigma and life lived is a fixed one that becomes unavoidable.

This stigma that has marginalized leprous sufferers and their families is rooted in fear and misunderstanding of the disease. The more knowledge and understanding that is present about the individual and their disease, the less likely for the individual to be stigmatized. Contrary, the more distance, and less knowledge that is possessed of an individual and their condition, stigmatization becomes a more probable outcome (Jones & Davis, 1965; Kelley, 1971).

3.4 Stigma and Social Interaction

Sociologist, William James believed that some roles we choose for ourselves while other roles are prescribed for us by virtue of our position in life. James proposed that the “development of behaviour” is seen as roles, and these roles serve the purpose of simplifying the task at hand (Solove, 2007: 68). James ideas were analysed and developed by numerous sociologists; notable through the work of Goffman. In Goffman's work *The Presentation of Self in Everyday Life*, published in 1959, an in depth description and analysis of human behaviour and daily interactions

is laid out. In his work, Goffman explores topics of individual identity and group relations, giving attention to the performative and characteristic structure of society. Goffman uses the metaphor of theatre to describe his work in which he elucidates a “dramaturgical” theory of self, to explain the interactions between individuals.

According to Goffman (1959: 17), interactions are seen as “performances,” influenced by the audience and the environment. The performance is broken down according to the actors place on stage with the performance at the front being “part of the individual’s performance which regularly functions in a general and fixed fashion to define the situation for those who observe the performance” (22). Through the actions of the actor, they gain the ability to promote themselves as being a certain way and communicating a similarity to the observer or representing an idealized version of the character which reflects the values of society (45). In his work, Goffman quotes James (48) stating that, “...we may practically say that he has as many social selves as there are distinct groups of persons about whose opinion he cares. He generally shows a different side of himself to each of these different groups.” Therefore the actor seeks to control the perceptions of his audience segregating them into different worlds as they give off different impressions of who they are to different audiences. The front stage role calls for the actor to give off impressions that they maintain a set of standards in their activities. However, the divide between the front and back of the stage is made up of starkly different roles. The front can be looked at as the public side of the performance whereas the backstage role Goffman (1959: 112) defines as a “place, relative to a given performance, where the impression fostered by the performance is knowingly contradicted as a matter of course.”

In his study, Goffman uses the metaphor of performance to communicate the different roles that individuals assume depending on their positioning on stage. The study considers the difference that occurs when individuals appear in front of others, on front stage, and when they remain back stage. This concept of front and back stage behaviour can be contextualized and examined within the context of a leprosy colony.

Due to MDT, children living in leprosy colonies are generally leprosy free. Being free from the physical marks of the disease children have the ability to control the perception society has of them. Presenting themselves as both front and back stage actors, children from the colonies seek to control their identity through impression management. To a degree, children can mask or control their true identity to achieve acceptance from the outside world. Despite increasing levels of integration occurring among the younger generation within the colony, their identity is ultimately tied to the colony. Within the confines of the colony, or the back stage, there is no longer the need for performance, and a different form of presentation (presumably more truthful one) occurs. Their position on 'stage' dictates the roles that are required of the individual as they shape themselves around the type of audience they come into contact with.

3.5 Stigma of Association

The stigma associated with leprosy stems from an attribute held by an individual (disfigurement), however, this stigma also attaches itself to those who bear no physical resemblance of the disease but are associated to a bearer of the disease. Stigma is therefore seen as being present due to something in the person and not as a physical label that is affixed and visible present. Stigma therefore becomes a "process of devaluation" rather than thing since "the qualities on which stigma operates (e.g., manner of speaking or acting) are essentially arbitrary" and the labels carried by stigmatized individuals "do not naturally exist but are created by individuals and by communities" (Maluwa, Aggleton & Parker, 2002: 4).

Stigma in relation to leprosy presents a unique case as stigma and what society labels as spoilt begins at birth. Stigma is woven into the lives of those from leprous backgrounds regardless of the visible presence of the disease, but the stigma is present due to the association. According to Heijnders (2004: 3), "After a person is labeled as leprous, there are negative social consequences for this person and his or her family. Stigma marks the possessor as socially unacceptable or as an inferior being and the effect of being labeled in this way is that people's stigma can come to dominate the

perception that others have of them and how they treat them.” Labels have been given to this stigma of association referring to it as an, associative stigma (Mehta & Farina, 1988) or in Goffman’s terminology, a courtesy stigma (1963). Goffman (1963: 43) expands on the concept of a courtesy stigma as a condition experienced by:

The individual who is related through the social structure to a stigmatized individual – a relationship that leads the wider society to treat both individuals in some respects as one. This, the loyal spouse of the mental patient, the daughter of the ex-con, the parent of the cripple, the friend of the blind, the family of the hangman, are all obliged to share some of the discredit of the stigmatized person to who they are related.

Once linked to such a stigma the marker becomes inseparable from those closely associated with him thus causing them to be marked (Mehta & Farina, 1988). Those who are marked and associated carriers experience a life altering phenomenon as their lives become impacted within social settings, mobility, relationships, marriage and in their ability to attend and participate in social and religious functions.

3.6 Leprosy and HIV/AIDS: A Comparison

AIDS is the modern-day leprosy...there are people who have the same attitude towards AIDS patients today that many people had toward leprosy patients one hundred years ago.

General C Everett Koop

The HIV/AIDS pandemic, frequently referred to as modern leprosy is the most common disease associated with fear and anxiety in society. The distinctive stigma and rejection that has been associated with leprosy overtime is no longer confined to leprosy but extends to the sufferers with HIV/AIDS.

Throughout history, a visible medical stigmata has been relied upon to shield society from the outbreak of disastrous endemics. This visible stigmata makes it possible to identify and treat sufferers of the respective disease and therefore can be classified as a good stigma (Brand, 1993: 316). However, this stigma has progressed

from being a medical indicator to a social indicator of fear resulting in a negative stigma. Although HIV/AIDS and leprosy have vastly different medical components, the fear of contagion in relation to both is rooted in misconceptions as "neither disease is highly infectious, except to a specific at-risk groups" (Brand, 1993: 317). Although the specifics of the diseases vary, strong social similarities exist and an overlap is seen in the negative impacts of stigma which result in rejection and marginalization. Therefore, it is useful to consider the long standing stigmatized disease of leprosy as the failed and successful methods used in studying the disease can be implemented with other similar disease (HIV/AIDS, Mental Illness)

As with leprosy sufferers, HIV/AIDS sufferers experience both felt and enacted stigma which have consequences on how the impacted individual organizes his or her life. Similar to leprosy, "prejudiced thoughts frequently lead to actions or inactions that are harmful or that deny a person services or entitlements" (Maluwa, Aggleton and Parker, 2002: 6). HIV/AIDS has become a highly politicized topic and unlike leprosy, has received much attention. Similarly with both diseases, "stigma and discrimination remain among the most poorly understood aspects of the epidemic[s]" (Parker and Aggleton, 2002: 1).

Unlike leprosy, the HIV/AIDS epidemic has only "developed during a period of rapid globalization and growing polarization between rich and poor" (Castells 1996, 1997, 1998). Parker, Easton, and Klein (2000) illustrate the age old form of social exclusion visible in the construct of leprosy colonies is presently being manifested through reinforcing "pre-existing social inequalities and stigmatization of the poor, homeless, landless, and jobless. As a result, poverty increases vulnerability to HIV/AIDS, and HIV/AIDS exacerbates poverty" (Cited in Parker and Aggleton, 2002: 2). In highly stigmatized context, the "fear of HIV/AIDS-related stigma and discrimination may cause individuals to isolate themselves to the extent that they no longer feel part of civil society and are unable to gain access the services and support they need" (Daniel and Parker 1993). Furthermore, this stigma transcends beyond the targeted suffer and Kowalewski (1988) shows that a:

similar stigma linked to leprosy and HIV/AIDS is that of association. Stigma associated with HIV is contagious and groups such as gay men are guilty by association and report 'courtesy stigma'; carers and family members may also share the stigma of AIDS and are likewise discredited and suffer enormously as a result of loss of friends and harassment (Cited in Green, 1995: 558).

The treatment and outcome of stigma in both leprosy and HIV/AIDS possess similarities. In regards to the research pertaining to this study it would be useful to compare and contrast findings that exist with the stigma of association that is experienced by family and friends (and groups) associated with individuals with HIV/AIDS and leprosy.

3.7 Literature Gaps

Since Goffman (1963) book, *Stigma: Notes on the Management of Spoiled Identity*, there has been a substantial growth in the academic work on stigma. However, the work has been limited due to complexity of defining stigma. Moreover, a vast portion of the work has been focused on the "social cognitive aspects of stigma" which leads to an understanding of the "individualistic aspects of stigma" (Maluwa, Aggleton, Parker, 2002: 4). Limited attention has been given to studying structural conditions that reinforce stigma "excluding people from social and economic life" and therefore stigma has been seen as something in the person stigmatized rather than a designation that others attach to that individual (Maluwa, Aggleton, Parker, 2002: 4). The stigma associated with leprosy cannot be viewed solely on an individual level. The stigma of leprosy does in fact impact the sufferer on an individual level but the structural components of stigma must also be recognized. Stigma is a power based relationship that is dependant on social, economic, and political power (Link & Phelan, 2001: 375). Stigmatization leads to a loss of social power and reduces the individual to a place of subservience and an inability to address the discrimination they encounter.

In regards to this study a limited pool of research is present on the correlation between the structural components of stigma and its impact on those who experience

stigma through association. Most attention has been allocated to those who encounter the harsh and direct impacts of stigma with a lack of research focusing on those who are marked yet removed by several generations from the marker. Stigmatization of leprosy individuals has been explored by numerous studies. Little research has been done to investigate how stigma is perceived and experienced by those related and associated to the disease. Specifically, conducting research among children whose parents or grandparents are leprosy sufferers. Since leprosy has been curable for over two decades, much of the research has been devoted first to the medical aspects and secondly to the social conditions that the sufferers exist in. Considerably little data has been compiled on the status of those who are free of the disease yet live in the confines of a leprosy colony. With the drastically changing face of leprosy there is a need to conduct research among the offspring of the leprosy patients who are beginning to make up the bulk of leprosy colonies.

Additionally, there is a limited amount of research that focuses on stigmatized children in India and their access to education. Education is an essential part of the development and success of any community, and the ability to secure education needs to be documented. Children from leprosy colonies encounter hurdles based on their association with the disease. Yet without education, they will be condemned to a life lived in the economic depravity similar to that of their parents and grandparents. Therefore, education must be made a priority and as Mr. Taroor, former Under-Secretary General of the United Nations states, "In this 21st century, if we do not provide our children with education, then we as a society are tying our hands behind our back, handicapping ourselves" (The Hindu, 2007). Hence, there is a need for further research on stigmatized children and their ability to access education.

3.7 Conceptual Framework

Based on the academic literature explored in the literature review, I will be relying primarily on the work of Erwin Goffman to construct the conceptual framework. The conceptual framework will rely on Goffman's concepts of stigma exploring the theory of back stage/front stage stigma and drawing on the notion of courtesy stigma, or stigma of association. The definition of stigma used in

approaching this thesis is from Goffman's work, *Notes on Management of Spoiled Identity*. Stigma is defined as an:

attribute that is deeply discrediting within a particular social interaction and applies the term stigma to any condition, attribute, trait, or behaviour that symbolically marks off the bearer as *culturally unacceptable* or inferior, with consequent feelings of shame, guilt and disgrace (1963: 3).

This definition sets the foundation to explore the concept of stigma as it impacts children from leprosy colonies, specifically in their access to education. With a working definition of stigma in place, the framework in which stigma is being looked at, analyzed, and developed should be considered. Goffman's work on front stage/back stage behavior that communicates the roles and mask individuals assume depending on what is required of them will be used in studying children from the leprosy colony. The front stage performance, an act where impressions are created in public life can be seen in the ability that children from colonies have to belong to a leprosy colony yet mingle and partially integrate into the broader society. However, the back stage performances, those which are not intended for everyday life can be observed within the confines of the colony. When back stage, removed from the audience, the actors rehearse for their moments spent on front stage.

Link and Phelan (2001: 377) introduce an idea of a stigma that exists on a continuum impacting individuals in vary degrees and Goffman (1963: 43) speaks of a stigma that spreads out in waves of diminishing intensity. Goffman elaborates on a courtesy stigma that impacts kin and affiliated members of the stigmatized individual. Therefore it is useful to employ Goffman's notion of courtesy stigma which forces the intimate, a person who can be discredited based on kinship or affiliation with a stigmatized person, to assume the management control of stigma (1963). In using Goffman's concept of a courtesy stigma the obstacles children encounter based on their association to the leprosy colony will be investigated. This study will also seek to study how colony children are affected by and seek to manage this courtesy stigma.

CHAPTER IV

RESEARCH METHODOLOGY

4.1 Research Design/Methods

The research for this thesis is qualitative in nature, relying primarily on: 1) direct observation and 2) in-depth interviews. The scope of the research includes four main areas: 1) St. John's Leprosy Colony, 2) Gnanodaya School, 3) Singaperumalkoil/Venkatapuram community members, 4) Government/Non-Governmental Organizations. The details of each area of research will be expanded on in their respective sections.

In total, two trips were made to the research site to obtain the data presented in this thesis. The first data collection period was between the third week of June and the second week of July 2008 and the second data collection period occurred between the second week of September and the last week of September 2008. The interviews were primarily carried out in the local language of Tamil and translated and transcribed into English.

4.2 Research Site

The research took place in the southern Indian state of Tamil Nadu. The specifics of the research were focused in the village of Venkatapuram in the Kancheepuram district. Additional information was obtained in the neighbouring town of Singaperumalkoil and from both government and NGO's based in Chennai, South India.

4.3 Participants

4.3.1 *St. John's Leprosy Colony*

For the onsite research component of this thesis, the majority of time was spent in St. John's Leprosy Colony in Venkatapuram village. The data were obtained through the use of focus groups, semi-structured interviews, and informal interviews. The questions used in the interviews were semi-structured to provide a degree of flexibility to explore various issues that arose during the course of the interviews. Within the colony the informants interviewed included colony leaders, leprosy free individuals, leprosy patients, and children.

Two key informants who played an important role in the leadership of the colony were:

1. Mr. Sevagaperumal, the colony secretary
2. Mr. Venegopal, the colony leader

In-depth interviews were conducted with both participants and served to provide a historical overview of the colony and gain information on previous and current problems.

House to house surveys and semi-structured interviews were carried out in which 10 families were interviewed. Employing a semi-structured approach to the interviews gave the participants space to dialogue while purposefully posing questions to steer the conversation around topics including:

1. History of leprosy in their family
2. Livelihood
3. Education
4. Attitude towards local community/colony

Two focus groups were held comprising of seven to nine colony members, which included both males and females, leprosy affected and leprosy free, and old and young participants. A large colony discussion was organized that stemmed from the topics of conversation addressed in the focus group setting. The colony discussion involved 50 plus individuals and lasted for two hours. The discussion included issues of identity, stigma, social opportunities, education, discrimination, hopes, the government's role in leprosy care, and the future of leprosy colonies.

4.3.2 Gnanodaya School

Time was spent at Gnanodaya School, a co-ed school dedicated to assist healthy children from leprosy colonies and economically depressed conditions. At the school, semi-structured interviews were conducted with 20 students from 8th – 10th standard. The children interviewed were from both leprosy colonies and the local community with a ratio of 3:1. Two teachers from the 8th and 10th grade classrooms were interviewed. Mr.Thangaraj, the headmaster of the school, along with his wife, participated in several in-depth interviews providing current and historical data regarding Gnanodaya School. Interviews carried out with the children were semi-structured and questions were posed dealing with topics that included:

1. Background of the child
2. Attitude towards fellow students
3. Attitudes of families visitation to the hostel
4. Hope and aspirations for the future

4.3.3 Singaperumalkoil and Venkatapuram Community Members

Additional research was carried out in the immediate area surrounding the colony by conducting two in-depth interviews, one focus group, and a brief survey involving 43 participants. The aim of the research was to gain an understanding of the community's perceptions and attitudes towards leprosy patients and their families.

The survey constructed included the following questions:

1. Where does leprosy come from and is it contagious?
2. Are there any local cases of leprosy in this area?
3. Is it acceptable to give jobs to leprosy patients in this community?
4. Would you allow your child to attend school if there were children from a leprosy colony enrolled in the same school?
5. What is the best solution for those living with leprosy?

4.3.4 Government and Non-Governmental Organizations

Lastly, interviews were carried out with 11 individuals from eight organizations based in Tamil Nadu, including both Government (G), and Non-Governmental Organizations (NGO). All organizations interviewed were working among leprosy patients and their families locally and nationally. The organizations interviewed included:

National Leprosy Relief and Rehabilitation (NGO)
 Damien Foundation (NGO)
 Gremaltes (NGO)
 Swiss Emmaus Leprosy Relief Work (NGO)
 IDEA India (NGO)
 Little Lights (NGO)
 Central Leprosy Teaching and Research Institute (G)
 Padma Venkataraman (G/NGO)

The purpose of meeting with these organizations was to capture information that they might have gathered locally and nationally pertaining to social issues of leprosy. Further, data triangulation was able to be carried out as both primary research and secondary research was conducted. Triangulation aided in establishing credibility to the data secured.

CHAPTER V

RESEARCH FINDINGS

In the previous chapter the methods employed in obtaining data were discussed. This chapter gives an account of the data gathered using the specified research methods. The data collection encompassed a wide range of topics, with specific focus on three components of the original research: 1) St. John's Leprosy Colony 2) Stigma of Leprosy and 3) Children's Access to Education. The following chapter will be divided into the three main components listed.

The research in St. John's Leprosy Colony was carried out primarily through observation and in-depth interviews. Information in the opening historical narrative was gathered from three key informants: Mr. Sevagaperumal, the colony secretary, Mr. Venegopal, the colony leader and Mr. Thangaraj, the headmaster of a nearby school.

5.1 St. John's Leprosy Colony

Fifty kilometres south of Chennai,⁸ the town of Singaperumalkoil is situated in Kancheepuram district. Singaperumalkoil, most famously known for the Padaladri Narasimhaswamy temple, is also home to a leprosy colony. St. John's Leprosy Colony, a self-run colony, lies on the outskirts of Singaperumalkoil in the local village of Venkatapuram. The colony, home to 150 residents, is a five kilometre bus ride beyond the town hub followed by a two kilometre walk through unpaved fields. Although located near to the village, the colony stands separate from the local community. Formed in the late 1960's, this colony adopted the name St. John's Leprosy Colony. The colony's name does not reflect a religious affiliation, but rather is derived from the association formed in 1965 by leprosy patients in Saidapet, South Chennai.

⁸ Chennai is the fourth largest metropolitan area of India and the capital city of Tamil Nadu.

In the 1950's and 60's a number of leprosy patients came to Chennai needing employment because their families threw them out of their households upon discovery of the disease. However, as the disease progressed employment was no longer an option and the leprosy sufferers found themselves in Saidapet's Government Hospital seeking treatment. After being treated, the patients were discharged and displaced, struggling to secure work or shelter. Thus began St. John's Leprosy Patients Rehabilitation Association which encouraged the formation of the colony. From inception, the association's aim has been to provide medical and social support to the leprosy patients and their family members. To achieve this, the association began to build medical and social support systems relying on local donors. After being registered under the Tamil Nadu Government in 1979, the association began to draw on foreign funding.

The village of Venkatapuram, situated five kilometres east of the main train line, has been historically known as a quiet, economically depressed, agrarian community. A majority of the inhabitants from the village hold quarry or concrete mixing jobs, both of which are labour intensive and are known as occupations of individuals from poor and low caste backgrounds. St. John's Leprosy Colony is a recent addition to the village of Venkatapuram. In 2000, the colony was established in Venkatapuram as a transplant of the urban leprosy colony that once existed in Saidapet, Chennai. According to Mr. Sevagaperumal, the secretary of the colony, "the relocation was due to the poor facilities and deteriorating living conditions in Saidapet." At the time of relocation, Dutchdek In Kinder (DIK), a German based NGO sponsoring the association, became involved in additionally supporting the colony. Upon request from the colony members, DIK selected a location and purchased five acres of land to build houses for the new colony. In a joint effort between St. John's Leprosy Rehabilitation Association and DIK, the construction of 50 houses in Venkatapuram began in 1999.

Talk and speculation of the new additions to Venkatapuram began prior to the relocation of the colony. The reactions in the community started to heighten with the visible construction of the colony houses. The community members began to voice

appeals to build the colony elsewhere and several members threatened to block construction. However, no direct action was taken.

The land purchased for the colony fell within the limits of Venkatapuram village and therefore by law, became an assumed sector of the community. The local gram panchayat⁹ sought to include this addition to the community by arranging to distribute voting cards among them. Several facilities¹⁰ were to be allotted to the colony, yet they stood independent from the local community, which would ultimately aid in keeping the colony isolated and self contained.

In 2000, the residents from St. John's Leprosy Colony relocated from Saidapet to the new colony in Venkatapuram. The shift from an urban to rural lifestyle proved to be challenging as the colony members found themselves adapting to a starkly different reality. While living in the city, the colony members were able to access the conveniences of the city, however, the rural agrarian community lacked adequate transport, unpaved roads and basic social services. The first year of the colony's establishment in Venkatapuram proved to be a turbulent adjustment for both the colony and community.

5.1.1 Demographic Data

St. John's Leprosy Colony consists of 150 residents, establishing itself as one of the larger colonies in Tamil Nadu. The population consists of a mixture of leprous and non-leprous individuals with three generations represented within the colony. The age range spans from a new born child to several leprosy patients between 65 and 70 years of age.

⁹ Gram Panchayats are local government bodies that exist at the village level in India.

¹⁰ The colony members were issued cards to vote during elections, and in addition the gram panchayat worked to install a pump within the colony as problems arose in the community when colony members began to fetch water from their source. Further, a separate burial ground was allotted to the colony.

Table 3. Population of St John's Leprosy Colony

St. John's Leprosy Colony Inhabitants	
Children (under 15)	40
Leprous	40
Non-Leprous	70
Total	150

Similar to the family structure in the surrounding village, a colony household comprises of the nuclear and extended family. On average, there is one leprosy patient per household and in all but one case; the leprosy-affected persons represented the grandfather/mother in the house. All households are monogamous, however, comments made by both men and women suggest that the culture of the colony doesn't strongly condemn men having mistresses in other colonies. All the leprosy sufferers who married before the disease occurred were left by their husbands/wives. However, all have remarried members from St. John's Leprosy Colony and other colonies in Tamil Nadu.

Within the home, the responsibility of caring for the leprosy affected falls on the daughter-in-law or daughter of the patient. Her responsibilities require her to bathe, feed, clean, and bandage the wounds of the patient. In the colony, men are the breadwinners and head of the household.

It should be noted that there are no rules that force people to stay within the colony yet a strong culture of belonging exists. With the prevention of new leprosy cases and the aging of the current patients, the face of St. John's Leprosy Colony will portray a starkly different reality in the next 15 – 20 years. Even now, there are families in the colony who have no living family member with the disease; however, they remain in the colony. A middle aged father explained that:

...once upon a time we had a leprosy patient in my family, but he passed away. Yet still, we will always be considered apart of this community. It's like a tree, [points to a small tree in the distance], if you cut it down, more branches will grow from it. We are like this tree – the disease was once in our family and we will always be tied to it.

Despite being free of a diseased person within the family, identity appears to be deeply rooted and remains within the leprosy colony.

5.1.2 Infrastructure

The members of St. John's Leprosy Colony attribute the strong infrastructure of the colony to the support received from outside agencies. Colony members state that the government has done little to help and treats them as forgotten citizens. The colony is three kilometres from the main road and on approaching the colony, the last two kilometre stretch is unpaved and in poor condition. However, the overall appearance is well maintained.

The construction of the colony appears well planned. With three rows of houses totalling 50 homes, there is a house for each family. Each house is supplied with electricity, lights, and a fan. Communal bathrooms are located behind the house and are shared by several households. The sewage system is enclosed creating a clean and healthy environment. Near the back of the colony, adjacent to the plot of cultivated land, is a bore well. There is a pump within the colony from which water is used for cooking, bathing, and washing. The land on which the houses are built is registered in DIK's name. However, as of September 2008, the colony members had been informed that they would receive bond papers signing ownership of the house and land into their names within the next six months.

Although the government provides the basic social services, the colony members continue to hold a negative view toward the government. Despite the negative view held by the colony members towards the government, it is the government who is responsible for supplying electricity, water, and clearing out the colony's septic tank. One of the reasons behind this negative view of the government is attributed to the fact that the government services are not supplied free of cost and the colony members pay monthly electricity, water, and sewage removal fees to the

government. Besides the government provided services, nearly all of the infrastructure has been supplied free of cost and maintained by outside organizations.

The cost of living within the colony is relatively affordable due to the financial support provided through DIK. Because DIK built the houses, there is no monthly rent bill to be paid additionally; DIK supplies monthly bags of rice and Rs. 250/- (US \$6) of spending money to each family. Medical expenses are covered and a doctor, paid through DIK, visits the health clinic on a monthly basis.

From the appearance of the colony grounds, sewage system, water supply, electricity, and houses it can be said that this colony has a good level of infrastructure. Additionally, upkeep of the colony is maintained by the inhabitants and appears to stand independent from assistance of outside organizations.

5.1.3 Religion

The three main religions practiced within the colony are: 1) Christianity 2) Hinduism and 3) Islam. Christianity was found to be the dominant religion, followed by Hinduism and a small percentage of members practicing Islam. A majority of the inhabitants have retained their birth religion, yet there have been cases of conversion that occurred after moving into the colony, showing mobility in one's religious affiliations. This mobility is most commonly seen to transfer from Hinduism to Christianity. Christian boarding schools that enroll children from a leprosy background and religious groups supplying provisions to the colony appear to play a significant role in introducing Christianity to the inhabitants.

Within the colony a Christian church and a Hindu temple have been constructed. The temple is used on a regular basis for religious ceremonies and pujas,¹¹ whereas the church is used less frequently. The Christian population in the colony attend a local church in Venkatapuram. According to leprosy patients from

¹¹ Puja's or Pooja's serve as a religious ritual for Hindu's that serve as a means of offering praise, thanks, and supplication to God.

the colony, the Hindu members of the colony prefer to worship at home as “we are a little cautious of going to places of worship outside the colony...people won’t say anything but we feel somewhat uncomfortable.” Although data does not clearly reveal this, based on the responses, a higher religious tolerance seems to be present among Christians outside the colony in comparison to those of the Hindu faith as colony members are apprehensive about attending local temples.

5.1.4 Caste

The colony is predominantly made up of individuals from Scheduled Caste¹² and Other Backward Classes.¹³ The hierarchy associated with caste outside the colony holds little significance or importance to the colony members. A male leprosy patient stated:

...when we were normal we used to view ourselves by our caste, now that doesn't matter. We first see our disease, this is our identity and we no longer identify with our caste. People outside the colony see us as removed from caste, we are treated as untouchables.

Other interviews coincide with the above statement suggesting that a leprosy patient's caste is no longer valued after they become associated with the disease. The son of the colony leader stated that, “in the colony, a person's identity is first and foremost as a leper, second comes religion...but then again, caste is removed from religion.”

The loss of caste is experienced by leprosy patients and non-leprosy patients living within the colony. Although the non-leprosy patients are removed from the physical deformities the patients encounter, they appear to experience the same loss of identity and worth that a leprosy individual experiences. Within the colony, caste holds no importance and identity becomes rooted within the disease and their

¹² The population grouping that are explicitly recognized by the Constitution of India previously called the “depressed classes” by the British, and otherwise known as untouchables.

¹³ Other Backward Classes are described as socially and educationally backward, and the government is enjoined to ensure their social and educational development.

families. Therefore a hierarchy based on caste appears to be non-existent within the colony.

5.1.5 Leadership

The members of the colony were found to be well organized with a leadership structure in place consisting of a nominated committee. The committee is comprised of a colony leader, secretary, and treasurer who are responsible for the care of the colony members; implementation of rules; handling of finances; decision making; and distribution of donations. The present colony leader appears to be well liked, respected, and supported by the colony.

Every year the colony holds a self organized election to vote in a leader, secretary, and treasurer. To run for the head position of colony leader requires that the individual be: 1) male 2) have visible deformities from leprosy and 3) able to read and write. Once elected, the leadership team acts as a collective voice within the colony. The colony leader, carrying the most responsibility, represents the colony at the bimonthly Leprosy Patients Rehabilitation Guild meeting in Chennai, in which 42 colony leaders throughout Tamil Nadu attend. The purpose of Guild meetings are to discuss problems and challenges faced within the colonies, collect financial contributions for the Leprosy Patients Rehabilitation Guild, discuss events within the leprosy community as well as provide a space for colony leaders to bring requests on behalf of their colony.

In addition to the Guild meetings, all members of St. John's Leprosy Colony gather weekly to discuss issues and projects pertaining to the colony, upcoming marriages, funerals, and other matters raised by the members. During the meeting, each family is expected to contribute Rs.10/-(\$US .25) to the *sandha*.¹⁴ Payment into the community *sandha* qualifies them to access the pool of money if there was a situation in which financial assistance is required. The money is generally used

¹⁴ *Sandha* is the membership fee paid to remain enlisted as a member within a group.

towards funeral, marriage, and emergency expenses within the colony and is granted to the individual based on group approval.

5.1.6 Livelihood/Economics

Within St. John's Leprosy Colony there are a variety of occupations that have been secured by the inhabitants. The occupations of colony members range and are dependant on the following factors:

1. If the patient has deformities
2. Education level
3. Location of where employment was sought
4. Privately supported ventures

5.1.6.1 Patients with Deformities

There are 40 leprosy affected patients in St. John's Leprosy Colony that carry the characteristic deformities associated with the disease. A majority of the patients were diagnosed with the disease in their 20's, during the pre-MDT era. Before contracting the disease they were engaged in professions such as farming, cattle rearing, painting, printing, and managing businesses. Currently, the average age of the patients with deformities is 60 years.

Those who are leprosy affected have found it impossible to secure work and are unable to survive on the government's monthly disability pension of Rs. 400/- (\$US10). The expenses of electricity and water exceed the 400/- allowance and yet to be added into monthly expenses is the cost of transport, food, unexpected occurrences, and family savings. Thus, in order to meet their needs, 38 of the 40 patients have resorted to begging. All of the leprosy affected beggars voiced an initial discomfort towards begging, but now, after 30+ years, it has become an accepted way of life. All but two of the leprosy patients in this colony beg three to six days a week. The two that remain in the colony do so because their physical deformities make the two hour walk to the train station virtually impossible. The patients who beg leave

the colony together in the early morning, and disperse to various train stations, bus stands, markets, and places of worship. The city of Chennai is often the desired destination as begging tends to yield more money here. The income generated through begging is kept by the individual for themselves and their families, and not put into a common pool.

Both adult male and female leprosy patients earn a living through begging. Begging is not seen as an occupation or a choice for the children from the colony. The leprosy affected individuals expressed a desire to quit begging if an alternative was provided. Yet, due to the physical limitations and fear attached to the deformities, hope of an alternative occupation appears impossible.

5.1.6.2 Education Level

An individual's education level strongly determines the type of job they are able to secure. In the colony, there are a handful of healthy, leprosy free males who are employed within the main city of Chennai. All of the individuals with jobs had the chance to attend boarding schools and graduated with good grades. These men have secured employment in the cancer institute, as a government employed secretary, and other offices. Individuals with less education obtain work as manual labourers.

5.1.6.3 Location of Sought Employment

Three women from the colony secured jobs as cleaning ladies in Singaperumalkoil. However, all three jobs were terminated when the employers discovered that the resident location of their employees was a nearby leprosy colony. The women reported that due to the type of occupations typically secured, colony women tend to be laid off from jobs at a faster rate than men. Men generally secure outdoor labour intensive jobs, with a group of other men where man power is required. Whereas colony women typically secure jobs cleaning within a home, placing them within an intimate setting of individuals from outside the colony.

5.1.6.4 Private Supported Ventures

Along with the purchase of colony land, DIK bought ten acres of land near the community to be used for agriculture. Agriculture projects provide employment for colony members and the produce cultivated is bought by the neighbouring school. Cows and goats have also been purchased as an addition to this venture. Revenue generated from the agriculture and livestock program provides a small sum of money to cover various expenses. This DIK initiative employs 15 families within the colony.

5.1.7 Social Participation

There are varying degrees of social participation and interaction with the outside community. The children of St. John's Leprosy Colony appear to be integrated to a much greater degree than their parents or grandparents have known. One of the primary reasons for this higher level of integration with the local community is due to attending schools in the local community of Venkatapuram.

The second generation, occupying the middle age bracket in the community, have established relations within the community. These relations were initially created out of economic necessity and over time the levels of social interaction continue to grow. A medical clinic was set up through the donors to provide treatment for the leprosy patients and also to provide free medical checkups to the local community. This service has served as a platform for interaction as the community members frequent the medical clinic. Further, the outside community attends the religious functions and celebrations organized by the colony. But, respondents noted that those who attend such functions leave early as they are unwilling to eat food prepared by the colony people or drink from their water source.

The leprosy affected individuals that make up the colony elders and first generation of inhabitants are those with the lowest level of social interaction and participation. The interviews revealed that despite the gradual changes occurring in

society's treatment of leprosy patients, isolation was still preferred by the leprosy affected and shame of self was repetitively mentioned.

5.2 The Stigma Associated with Leprosy

Various indicators have been associated with leprosy, such as uncleanliness and begging. Yet most widely identified are the markers of leprosy colonies and physical deformities. Indian society's interaction with leprosy sufferers tends to occur when there is the safe space between giver and beggar. If interaction occurs between a leprosy individual and a member from the broader society, the context is generally begging. Leprosy patients, accepting the low status cast upon them by society, seek handouts from passerby's and society interacts with leprosy patients.

Thus, for many their understanding of leprosy is synonymous with begging, disfigurement, social exclusion, and stigmatization. This view of leprosy only perpetuates the stigma as people stay oblivious to the readily available medical ability to treat and cure the disease.

5.2.1 Thoughts on Leprosy and Integration in Singaperumalkoil and Venkatapuram

To investigate the stigma attached to leprosy, data was collected in the form of surveys from 30 respondents within a five kilometre radius of the colony. The respondents ranged in age, occupation, sex, religious background, and education level. The style of question asking remained consistent and no cues were provided to guide or manipulate the answers. To gather data on the local understanding of leprosy, 30 informants were asked three main questions.

- Where does leprosy come from?
- Is it acceptable to provide jobs in this community for members of the nearby leprosy colony on the grounds that they are healthy or receiving medication/check ups?
- If you had a child, would you enrol him/her in a school that admitted healthy children from leprosy colonies?

The answer in the form of tables is shown below:

Table 4: Community Survey: Causes of Leprosy

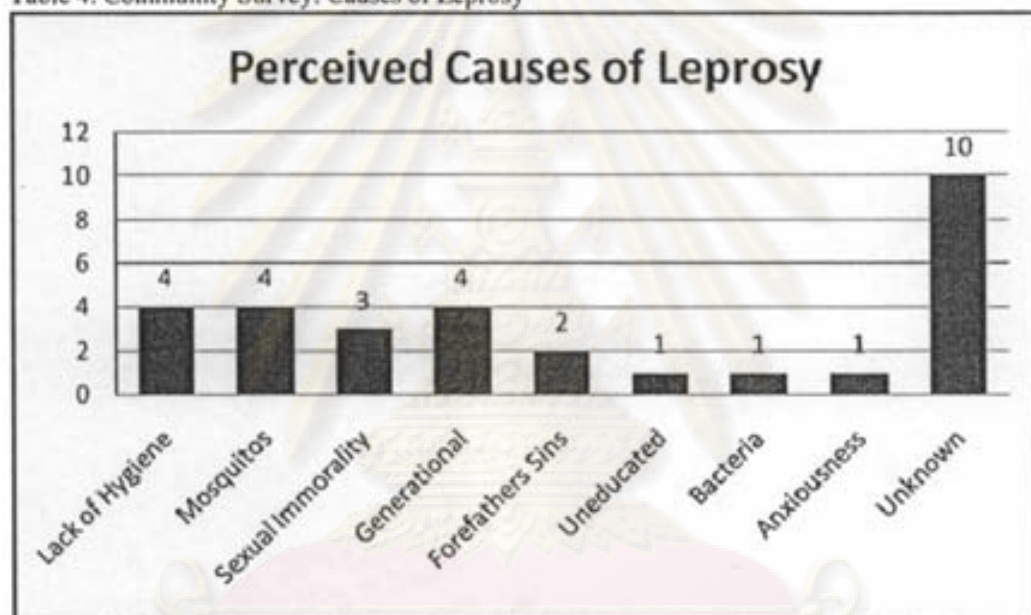


Table 5: Community Survey: Integration of Jobs

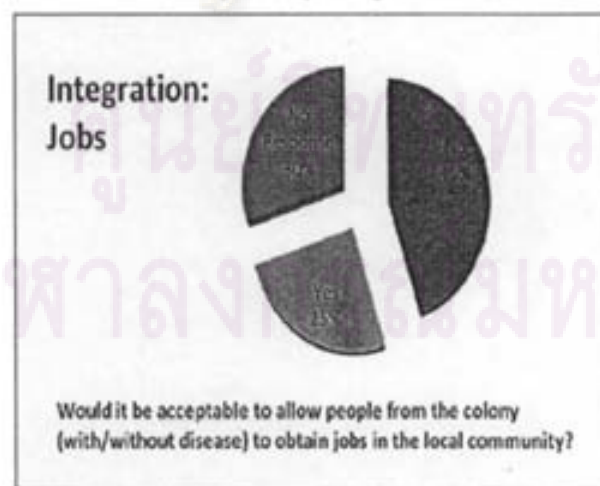
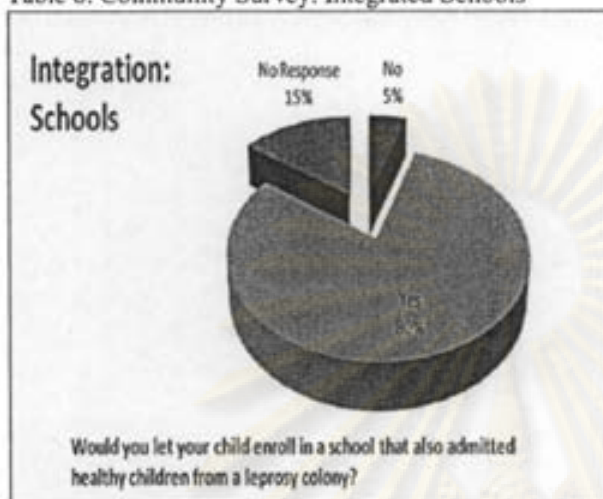


Table 6: Community Survey: Integrated Schools



In examining the surveys, a relationship between the results in table 4 and table 5 is noted. Table 4 displays a marked level of unawareness and misconceptions in regards to the origins of leprosy. This low level of knowledge corresponds with the high level of opposition communicated in regards to the integration of jobs as seen in table 5. Therefore, it can be suggested that ignorance of leprosy breeds fear and leads to a rejection of the affected.

The results of table 6 contrast with the results of tables 4 and 5. With 80% of interviewees affirming the idea of integrated education, there appears to be no correlation with tables 4 or 5. Through these results we see a marked difference in the level of opposition felt by adults and children from the leprosy colony. The stigma, present in all three generations, appears to be diluted from one generation to the next. The children, unlike their parents and even more so, their grandparents, possess a stigma that is able to be masked as they own the ability to integrate with society. The results reflect Goffman's analysis of back stage/front stage, illustrating the increasing ability children have to take a place and be aware of how to interact on both stages, gaining the approval from inside and outside the colony.

5.2.3 Thoughts on Leprosy and Integration in St. John's Leprosy Colony

Collecting data within the colony on people's perception of leprosy was done primarily through a group discussion with 50 colony members, both leprosy and healthy. Due to the unpredictable schedules of begging and outside responsibilities, discussing these questions was best done in the group setting.

When asked about the origins of leprosy the colony members, particularly the patients, readily admitted they did not know but had assumptions that alluded to the disease being present based on: forefathers sins, cursed from God, generational, and contracted through bacteria.

On matters of integration the common response among those who had no physical deformity was that integration would be ideal but the chances of this happening were very unlikely. A different response was gathered from the leprosy affected. The patients spoke of the fear of their deformities that was held by the surrounding community. The interviews revealed that the affected were shameful of their deformities and carried a lack of self worth that was only reinforced by local attitudes. Due to the attitudes of society and self stigmatization, social exclusion becomes desired among the leprosy affected.

There is a degree of economic integration occurring with several leprosy free individuals securing jobs as painters, builders, and manual labourers within the village. DIK has created a livestock initiative with the purpose of income generation. The milk is sold to a nearby school. The local village people are also purchasing this milk as it is sold at a cheaper rate than found in the town. This initiative has created integration out of necessity as the colony and community depend on one another. The colony is hopeful for their children to reap the benefits of integrating, with the expectancy that the children will be able to secure good jobs and return to support their parents.

5.3 Education

5.3.1 Education Level

The average level of education for members in the first generation bracket is the 3rd standard. Although exceptions exist where a 6th – 8th standard education was secured, this is not the norm. The majority of the members in this generation bracket are illiterate. According to a leprosy patient:

...when we were young and we contracted the disease there was no medicine available, there was no awareness and we were poor...going to school became impossible for several reasons. Also, back then there were no hostels and if we went to normal schools people would have been afraid.

A significant increase in the education level is seen within the second generation. There are roughly 70 individuals within this group and among them ten have secured a higher education (12th standard with a few college degrees). Nearly all individuals in this generation bracket had the opportunity to attend school, predominantly being enrolled in Christian boarding schools. According to informants, boarding schools were a necessity if education was to be obtained. Boarding schools provided an education away from home and the education was commonly free of cost or subsidized. In an interview with Mr. Srinivasan from Swiss Emmaus Leprosy Relief Work he commented on this trend stating, “I would say nearly 90% were in boarding school. You see, most of their parents are uneducated. The children...if they stayed at home, who would be able to help them in their studies?”

Presently, a majority of the current generation in the colony is enrolled within school. Because the children are still attending school, it is not possible to accurately measure the final level of education achieved. Yet, considering the current enrollment and negative dropout rates, it can be projected that this generation will secure the highest level of education with a handful of

educational success stories beginning to emerge.¹⁵ Presently, all 40 children in the colony under 15 years of age are enrolled in school.

5.3.2 Perceptions of Education

5.3.2.1 Parents

Among the parents and grandparents of St. John's Leprosy Colony, education is perceived positively. Although the majority have only secured a low level of education, parents are keen to ensure that their child attends school and that a good level of education is received. Despite the economic constraints in the colony, education appears to be prioritized above money. This can be seen in the choices the colony members make, one of which is represented in the fact that children are not taken for begging even though their presence could double the income generated. In some cases, more than prioritizing education, families are seen to be making sacrifices in order to secure a high standard of education for their children. Selvi, a mother of three from St. John's Leprosy Colony, is well aware of the limitations that are coupled with growing up in a colony. She herself grew up in a leprosy colony and was eventually sent away to a government boarding school to receive an education, primarily due to the economical strain that she would add to her family if she remained. Her husband's childhood echoes the same story. In an interview, Selvi communicated why she and her husband made the decision to enroll their eldest child in a private school even when a free educational alternative exists.

... my eldest who is 14 is in a private school. Gnanodaya is a good school but my husband wants him to get an English education... An English education will provide him with far more opportunities. So we choose to sacrifice, we have to pay school fees at the private school...yearly we have to come up with Rs. 5000/- (US\$145) and then Rs. 100/- (US\$3) on a monthly basis and during exams there is also a fee. Thankfully my husband has secured a decent job...it is still is a struggle, but a good education is very important for our family.

¹⁵ There are a several young adults in the colony that have recently finished high school and are hoping to apply for funding to attend university.

A common thought communicated by parents in the colony was that if money is invested into education, this will give the children a chance of securing good jobs, and in turn, the child can return to the colony and support them.

5.3.2.2 Children

Children in St. John's Leprosy Colony have a positive view of education and an awareness of the future it can provide. As children often do, the children in the colony have big dreams of what education can achieve for them. The children, ranging between 13- 16 years old spoke of dreams of being engineers, doctors, movie stars, police women, teachers, and social workers. The voiced ambitions of the children nearly always followed with an explanation of how they would use their income to support members of the colony. Nine out of ten children interviewed expressed a desire to remain in the colony after they finished their education, communicating loyalty to their family.

The population of children within St. John's Leprosy Colony are free of leprosy and deformities. Because there is no physical manifestation of the disease, the most feared and stigmatized indicator attached to the disease does not impact them. The parents expressed a relative degree of acceptance and lack of problems that the children encountered from the broader society. However, children were aware of their identity and what this might communicate to the public. From an early age, deformity or deformity free, a spoiling of one's identity occurs. A colony member who is leprosy free and raising a healthy child, informed me of the struggle, stating that:

...this generation is getting an education, and they will grow up and have the opportunity to get jobs...their lives will be significantly different from the last two generations, and even though different, their thoughts will not change – the community will know who they are connected to and never fully accept them.

5.3.3 Physical Access to Education

Education has become a secure and accessible right for children between the ages of 5 - 16 from St. John's Leprosy Colony. The current enrollment rate of the 40 children from the colony presently stands at 100%. Within a five kilometre radius the three types of schools that are accessible to the colony are: 1) Private School 2) Government Primary School and 3) Gnanodaya School. Each school offers a different level of education. The private school offers education from the 1st standard to 12th standard. Gnanodaya School offers education from 1st – 10th standard and the Government Primary School offers education from the 1st to 5th standard. Children from the colony can access all three school systems and their enrollment depends on personal preference and admission availability. The current breakdown of enrollment stands at:

Table 7: St. John's Colony Enrollment in Local Schools

Enrollment*:	
In Private Schools	5%
In Government Schools	25%
In Gnanodaya School	70%
Total Enrolled	100%

*Total number of students enrolled is 40

After the colony, the majority of my time was spent at Gnanodaya School which provides education from the 1st to 10th standard for 28 of the 40 children from St. John's Leprosy Colony. However, as noted, other schools in the community are also accessed and a brief profile of each will be given.

5.3.3.1 Private School

From the data collected, only two families have enrolled their children into the local private school which is five kilometres from the colony. In order to attend, there are annual fees and relatively high tuition rates that must be paid upfront. However, the price tag of private schooling provides the child with an English medium education. This, according to the parents, "provides our children with the chance of

accessing far more opportunities in life.” Both families that have enrolled their children in private schools were at one point part of the colony leadership, holding the positions of ex-secretary and the current colony leader. Admission for these children in private school was only gained in the last five years. It should be noted that those holding leadership positions within the colony are more probable to secure such educations as there is a higher access to financial resources as a result of being elected into leadership, creating an economical hierarchy within the colony.

5.3.3.2 Government School

The government school currently has 13 children enrolled from St. John's Leprosy Colony. The school is three kilometres from the colony and is predominantly made up of children from the village of Venkatapuram. The school runs from 1st to 5th standard and is government subsidized with the government taking responsibility for covering the teachers' salaries. Yet it requires that the students are responsible for the cost of their books, uniforms, meals and exam fees. Families report that although a decent education is secured, the school's facilities are poor and classrooms are over crowded. The government school's curriculum is in Tamil as is the communication between teacher and student. Admission for children from St. John's Leprosy Colony to the government school has only been made possible starting from the 2003 – 2004 academic year.

5.3.3.3 Gnanodaya School

The locally administered, foreign funded, co-education school currently has 28 children enrolled from St. John's Leprosy Colony. The school is located 150 meters from the colony and is comprised of children from leprosy colonies throughout Tamil Nadu as well as children from the local community. The funding of the foreign donors covers the salaries and maintenance cost of the school. Based on the economic background of the students, scholarships are awarded. The school provides children with free education from 1st – 10th standard, along with the provision of uniforms, text books, one meal per a day and book bags. The school follows a Tamil medium curriculum and English lessons have been introduced as an addition to the syllabus.

5.4 Gnanodaya School

There are several reasons behind the choice to focus my research on Gnanodaya School. Out of the schools that have enrolled children from St. John's Leprosy Colony, Gnanodaya has the highest percentage, with an enrollment of 70% of the colony children. Gnanodaya has been providing education to the children of the leprosy colony since 2001, whereas the other schools' relationship with the colony children started between 2003 – 2004. This gives Gnanodaya School a more comprehensive understanding and knowledge of the children from the leprosy colony. Furthermore, Gnanodaya staff members openly acknowledge that the school is integrated with children from leprosy backgrounds and the local community. The mixed population of students and the link to St. John's Leprosy Colony encourages further study.

Gnanodaya School in Venkatapuram was started in 2001 by the St. John's Leprosy Patients Rehabilitation Association. The school was originally birthed in response to the request raised by the inhabitants of St. John's Leprosy Colony. The plans for the school started when the members of St. John's Leprosy Patient Rehabilitation Association approached DIK, the German donor involved in building the leprosy colony, and requested that along with the construction of the colony, a school for the healthy children from the colony be built. Mr. Thangaraj, the headmaster of Gnanodaya School, stated that the reason behind this request for a school was linked to the struggle the parents had faced in trying to secure education for their children. Mr. Thangaraj explains that:

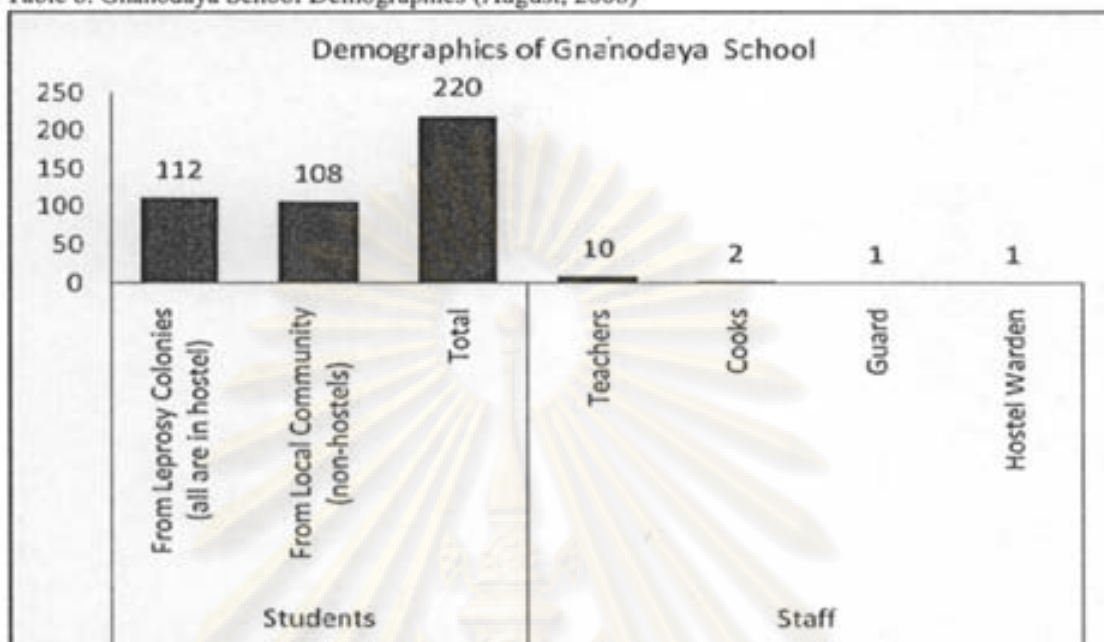
Our initial plan was to start a hostel to house the children from leprosy colonies in the area and send the children to a local government school, but when we approached the local government schools to seek enrollment for the next term they told us, 'if your children come to our school all the other children will leave because of the background of the children – they are from a leprosy colony' and no amount of negotiation on our part seemed to work.

No report was filed in regards to the government schools' response. Although legal action could have been taken up based on India's Constitutional commitment to 'Education for All,' nothing was done, and the response was accepted. Thus began the construction of a foreign funded school catering primarily to children from leprosy colonies in South India as well as intentionally opening its doors to children from the local community in the hopes of creating an integrated education.

The construction of Gnanodaya School began in parallel with the construction of the colony. Largely due to foreign funding, the school was far larger and grander than other schools in the area. The construction of the school also raised fears and questions in regards to the health of the children that would be attending from leprosy backgrounds. Prior to the opening, government officials came to inspect the school. According to Mr. Thangaraj, the officials told him that the school met the inspection standards but they were not to open if they intended to have a mixed population of students attending the school. Mr. Thangaraj responded to the officials informing them that the school was to be for healthy boys and girls from leprosy backgrounds and also open to children who fall into the lower economic bracket within the community. The officials, unable to push their request legally, left. Gnanodaya School, already known through the community, publicized the fact that students from economically disadvantaged backgrounds could apply for a scholarship and receive assistance for their education through DIK. The scholarship would provide the applicant with free education, one meal a day, uniform, text books, and a school bag. Despite the high standard of facilities and free education being offered, the first academic year saw an enrollment of children exclusively from leprosy backgrounds.

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Table 8. Gnanodaya School Demographics (August, 2008)



With the total enrollment rate at 220, Gnanodaya is nearing full capacity with room for only a few more students. Now, 8 years after opening, there appears to be little problem in attracting children from the local community. However, despite the positive interviews conducted with teachers, students, and parents, it appears that stigma related problems continue to surface from time to time.

In June 2007 the number of local children studying at Gnanodaya suddenly dropped from 100 to 85. According to Mr. Thangaraj, this was mostly due to fear in the parent's minds that was only encouraged by the government teachers who told them that their children were at risk of catching leprosy.¹⁶ In an attempt to address the misconception, Mr. Thangaraj informed the parents that their children were safe and there was no risk of contracting leprosy as the school is for healthy children from leprosy colonies. Yet, Gnanodaya still experienced a loss of 15 students.

¹⁶ When the local community began to enroll their children at Gnanodaya, the government school saw a significant loss in students. Since the number of government teachers in a government school is based on enrollment, there is a vested interest for those teachers to maintain a certain level of enrollment.

Gnanodaya School works hard to create an atmosphere of acceptance and equality among the students. Mr. Thangaraj expressed that “there is low self esteem particularly among the children from the leprosy colonies and we work to build worth in them.” The operations of the school are integrated and children study, play, and learn together. However, integration has its limitations even within this school. Initially, the parents from the community pushed for their children to be seated separately. This no longer appears to be a problem, yet the sharing of food appears to be too large an obstacle to overcome at this stage. Gnanodaya serves a daily meal to 212 children. The hostel children (leprosy background) eat together upstairs while the local children (non leprosy background) eat downstairs. The school has terminated the attempt to merge meal times as parents from the local community have protested every time a merge was attempted and threatened to pull their children out of the school. The aversion of sharing meals together is based on the knowledge that children are eating from a common set of plates. The local community has been led to believe that eating from a plate that at one point was used by a child from the leprosy colony is harmful and should be avoided due to the fear of un-cleanliness and contagion of the disease. Time was spent assuring parents that the children from the colonies are healthy and pose no risk to the other children. However, despite this, communal sharing of food appears to be too great a hurdle to presently overcome.

5.4.1 Gnanodaya: An Integrated School

Since its inception, Gnanodaya has been upfront about the acceptance of children from both leprosy and non leprosy backgrounds. The primary commitment of the school is to cater to children of leprosy affected patients as it is these children that face the greatest obstacle in securing an education. Gnanodaya is the only school of its kind in Tamil Nadu and hence, attracts children from leprosy colonies throughout India. The reason this school attracts colony children from throughout India is primarily due to the guarantee that education will be secured. Priority is given to two brackets of children, 1) those from leprosy colonies and 2) children in the local community who live in economically depressed circumstance. Furthermore,

specific attention is given to enroll children from colonies who are likely to face high levels of discrimination and economic challenges because:

1. Their Father/Mother is a patient currently undergoing treatment
2. Their Grandfather/Grandmother is a patient currently undergoing treatment
3. Related to leprosy affected person and not in 1 and 2.

Ultimately, Gnanodaya aims to cater to the neediest children. However, in doing so the school attempts to keep the school integrated in order to: 1) address the stigma carried by leprosy and 2) provide the children from the colony with a chance to integrate into the broader society. As seen, this process to establish an integrated school has not always been accepted and commotion continues to be raised when a more intimate integration is attempted (sharing of food).

In order to aid in integration, Gnanodaya makes it a priority raise the awareness level of leprosy among the local community by talking to the parents about the disease and addressing misconceptions. Importance is also given to stressing that Gnanodaya only accepts healthy children from colonies. Furthermore, Gnanodaya carries out medical checkups bimonthly, checking specifically for leprosy related symptoms in all the children. In the past, the medical screening has been carried out by Mr. Durai from the Central Leprosy Training and Research Institute, or CLTRI.¹⁷

However, as seen over time, integration began to occur with community members enrolling their children within the school. Mr. Thangaraj mentions that “there has been considerable change in the attitude and demeanour of parents from the community as more and more local children begin to attend Gnanodaya.” This change has been fostered through the efforts of Gnanodaya to reassure the parents of the precautions taken in dealing with the disease. However the change has been primarily brought on by the local children enrolled in the school that have all remained healthy and established friendships with children from the colony.

¹⁷ During the inspection, if white patches or discolorations in the body where senses are lost are found, a blood test is immediately performed at CLTRI which specializes in leprosy diagnosis. Once confirmed, they follow it up with MDT (multi drug therapy) treatment. Over the past 9 years, 8 children, 3 girls and 5 boys (all from colonies who had contact with the disease over a long period of time) were diagnosed and were treated successfully with no problems.

In order to examine this issue deeper, parents and children from leprosy and non leprosy backgrounds were interviewed. Interviews were conducted with 20 children, parents, and the headmaster of Gnanodaya School.

5.4.1.1 Schools Perceptions

As seen through the responses communicated in regards to sharing of food, it becomes clear that children from the colonies raise a level of fear in the minds of parents. However, significant hurdles have been overcome since the school's beginning and gradual progress in addressing misconceptions continue to be made. In the first year of running, Gnanodaya was unable to recruit local children and until the second year Gnanodaya remained a leprosy exclusive school by default. According to Mr. Thangaraj, the first local to enroll was the daughter of a lady employed at the school.

...the mother worked here daily and observed the children from leprosy backgrounds....in the same way when others interact with these kids their fear is broken. After the girl joined from the community, her friends enrolled. That year we had 10 students join from the local community. The 3rd year another 20 – 30 joined.

Mr. Thangaraj believes that schools like Gnanodaya are essential for the life success of children from leprosy colonies. "It is best to integrate for both children from leprosy backgrounds and normal students as it addresses the misconceptions and fears." When integration does not happen or is kept secretive, more problems arise. Reflecting on a past student, Mr. Thangaraj shared this story:

There is one boy who used to study here from Avadi. At that time we only had permission from the government to run the school till 8th standard. When he completed 8th standard we sent him on to finish his education at another hostel. This boy ended up running away because when the other boarders

found out his background they began to bullying him. The other boys would tell him, 'your father is a handicap, a leper'...

According to Mr. Thangaraj, this school provides the support that the children need, giving them interaction with the public, and work to invest dignity and worth in each child. This is done through coaching, encouraging them in their studies, and communicating the potential that they have. However, schools like this are rare, and Gnanodaya is the only school that provides and education for both leprosy patients and normal children from 1st – 10th standard in the state of Tamil Nadu. Since the school has only been running 8 years there are only a few graduates, but from the 4 student who have graduated, there are success stories of good jobs being secured and one student has gained admission into a local college.

5.4.1.2 Parents Perceptions

All the parents interviewed who have a child enrolled at Gnanodaya affirmed the quality of the school and the competitive educational atmosphere created. Parents from St. John's Leprosy Colony and the community who have children at Gnanodaya are more concerned that their child gets a good education rather than the fact that the school is integrated. Parents from the colony have placed high expectations on Gnanodaya and are optimistic that the chance to secure a good education will be followed by obtaining good jobs. Parents in the local community hold similar expectations and are pleased with the quality of education being secured. The education offered through Gnanodaya was communicated to be superior to the government schools in the areas. A father from the local community spoke of his daughter saying:

She's been going for nearly 7 years – we see no problem. It's a good school, the education is completely free. This school has good education, expects the kids to be on time...they really work with them to guarantee they succeed. The children are all healthy and there is no fear. I can't speak for the whole area, but for me there is no problem.

There was an absence of fear communicated in interviews with parents from the local community. Several parents indicated that initially there was apprehension, but now there is no problem and the school is providing their children with quality education that they would otherwise be unable to afford.

5.4.1.3 Children's Perceptions

Children from both the colony and community are aware that they attend an integrated school but this seems to carry little importance to them. Unlike the local children, all the children from colonies other than St. Johns Leprosy, board at the hostel while the other children are day scholars. Due to the close proximity of St. John's Leprosy Colony, all but 3 of the 28 children are day scholars, and walk to school as the community children do.

Accounts of bullying and teasing within the 10th standard classroom were communicated in interviews. However, the teasing did not appear to be aimed at a particular group of students. Rather, both community and leprosy colony children experienced teasing and bullying. The children are aware of one another's background, mainly because it is easy to divide the student into hostel boarders (leprosy background) and day scholars (local community). However, this has little impact on friendship. When talking to children from the colony and community and asking questions about their friends, it becomes clear that friendship lines are not homogenous. Murugan, from Johns Leprosy Colony studying in standard 10¹⁸ mentions that:

...we all mix now, my best friends are from leprosy colonies and from the local community. Outside problems exist, they separate, they don't have friendships, but we have good relationships here – this school is different.

¹⁸ The standard 10 classroom comprises of children between 15 – 16 years of age.

Parents of the 112 colony children who live in the dormitories come to see their children on visitation day which occurs once every three months. These visitations initially resulted in questions from the local children as they were introduced to their friend's family in which some of the members had leprosy. According to the children, visitations from their families serve as a reminder of where they come from, however this doesn't appear to be a fully negative reminder. S. Samitha, studying in the 10th standard talks about when her parents come to visit mentioning that:

Sometimes friends ask me about why my parents look that way [leprosy affected]... before in the beginning the other children didn't talk to us, they were a little scared ... but I didn't care, I wanted to see my parents, but now the kids accept me and my parents. Also I am studying well – many of my friends will come to me to get help... so I am fine, I have confidence.

Talking to students from the local community on the achievement level in the classroom, no group distinction appeared to be made between the intelligence levels of the community children or leprosy colony children. Rather, children spoke of members of their class who were tough to compete with, which happened to be both day scholars and boarders. Both sets of children appear aware of the standard of education they are receiving and both have hopes to eventually obtain good jobs and succeed.

In conclusion, there is an overall positive sense of integrated education. Integration, for the most part, is a non-issue among the children, yet the parents, who interact far less frequently with the colony children, seem to be more apprehensive. The 10th standard education level made available through Gnanodaya will provide strong occupational opportunities for the children. Although a 10th standard education holds weight when seeking job opportunities, the school donors are presently working to provide education until 12th and support students in securing college educations.

5.5 Post Education

For many within this generation, access to education has worked to equalize the playing field. Although a growing equality is emerging, education is not a complete fix to the problems that these children encounter. The stigma of association has not been erased through education and young adults from the colony find themselves encountering limitation and barriers because of this. Just beneath the surface of the increasing levels of integration, it appears that the stigma of leprosy is alive and impacts children even though they are two generations removed from the disease. For young adults the stigma most notably impacts them in areas of employment and marriage.

5.5.1 Employment

Having educational credentials against one's name proves to aid in the success of securing employment. However, accounts of discrimination in the work place still occur if the employer becomes knowledgeable of the individual's background. Therefore, in certain cases there is a need to conceal one's identity, or provide an alternative home address on the documents required for employment.

Within the colony it was agreed that education creates the opportunity to secure good jobs, however, this is not always possible without the assistance of the government or a Christian organization who initially mediates between the colony individual and the employer. This is true especially in areas near the colony in which people are knowledgeable of the colonies existence. Often to avoid this, members of the colony seek work in the city where people are unaware of their background. "Some of us will get jobs in this local area, but not everyone. Yet, when we move beyond this area, where people don't know our background, then everyone has a chance of securing a good job." (A young, leprosy free father).

5.5.2 Marriage

Marriage appears to be a topic laden with complications and expectations, particularly for those living in the colony. Within a leprosy colony, marriages are typically arranged by the colony leader selecting a suitable match with a young adult from another colony. Today, more than ever before, young adults in the colony are defying social norms and deviating away from the tradition of arranged marriages. Love marriages¹⁹ are on the rise between colony members and even more controversial, are the few accounts of love-marriages with individuals from outside the colony. Marrying outside of the colony is not looked upon favourably. According to an elder in the colony:

The committee won't allow the children to marry outside the colony, and if there is a chance of it happening we call a meeting. Our children understand that this cannot happen, they should keep marriage inside, marrying another colony member. Also, outside people will not consider marrying us as we are seen very, very lowly. If they did give their child to marry one of our children, their relatives would reject them as a family and especially reject the child. So why even face this? It is not worth it, instead of facing more rejection, they should simply follow the advice we give.

The opposition from the colony is based on the fear that if a love marriage were to happen with a girl from the outside, the new spouse would be unfit and fearful to take care of her in-laws' disabilities. The colonies' opposition to an outside marriage is primarily based around the demands of a spouse in caring for the diseased, avoidance of unnecessary additional rejection, and the security that comes in remaining with what is familiar.

¹⁹ Love marriages, in which a young couple initiate a relationship themselves goes against the traditional practice of arranged marriages in India.

Within the local community, marriage to a person from a leprosy background is unheard of. Even approaching the topic with community members raised much commotion. The idea of marriage brought forth strong feeling and opinions within the local community. The responses illustrated that the stigma attached to the disease has passed through generations and a marital alliance between a local person and an individual from a leprosy background is considered absurd.



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CHAPTER VI

DISCUSSION

This chapter will discuss the research findings gathered from three key locations: 1) St John's Leprosy Colony 2) Venkatapuram and Singaperumalkoil community and 3) Gnanodaya School. Information obtained from NGO's and government organizations will also be included.

6.1 Growing Up in a Leprosy Colony

The children growing up in St. John's Leprosy Colony find themselves straddled in-between worlds. With one foot imbedded in the leprosy colony and the other in society, these children have access to two realities, yet fully represent or belong to neither. Within the leprosy colony, these children belong, yet do not represent the deformities of leprosy. In the broader society, colony children can integrate, yet due to a spoilt identity, they do not fully belong. With the level of integration increasing, society's role in the children's lives is increasing; nevertheless, it is the formative years spent within the colony that strongly shapes the children. Children in the colony grow up immersed in a reality where grandparents possess severe deformities that are symbolized by fear. Begging is seen as a livelihood and a low level of education is the norm. Rejection from society and social exclusion is accepted. The stigma attached to leprosy becomes an assumed component of the children's identity. Despite being marginalized and separated from society, a deep sense of belonging and loyalty are fostered within the confines of the colony. This sense of belonging becomes inseparable from the shared loss of social identity experienced within the colony.

6.1.1 Self-Stigmatization

As previously noted through the work of Link and Phelan (2001: 377), the stigma of leprosy is experienced on a continuum - individuals are impacted in varying degrees. However, despite these differences in experiencing stigma, colony members share a spoilt/common identity. This spoilt identity that is imposed on an individual through society is eventually accepted and solidified by self. This acceptance creates a negative self image and as a result, the individual self constructs further obstacles to overcome. The stereotypes held by society are internalized by the targeted individual and result in a loss of self-esteem.

This self stigma is most evident among the first generation members in the colony who possess deformities of the disease. The stigma that follows the disease has led the sufferers to an abhorrence of self and a desire to remain in isolation. An elderly patient within the colony possessing physical deformities of the disease expressed that:

...separation is better as we don't face as much rejection. In a separate place we are free to just be. If we move to the community, we will be rejected, have to take blame for problems, and have difficult lives because of our disease.

Within the colony a stigmatization of self occurs which is continually reinforced by the fearful attitudes outsiders communicate towards leprosy individuals. This stigma has led to the acceptance of social isolation as the sufferers are deemed unacceptable to the outside world, and ultimately, unacceptable to themselves. This self-stigmatization is passed down through generations, with the concept of a spoilt identity being inherited at birth, for both leprosy and non leprosy children. From the research findings, it is evident that the children growing up within the colony experience discrimination, however, the notion of an internalized stigma appears to be continually decreasing among the present generation of children.

A paradox exists in the way individuals within the colony interact with and respond to stigma. Within the elder generation of individuals there is a marked level of indifference and apathy towards their situation. However, the children within the colony are beginning to question why they are not able to achieve what others have and respond to stigma with motivation and determination to succeed.

6.1.1.1 Children and Self Stigmatization

Children from St. John's Leprosy Colony are recipients of the stigma by association. This stigma of association can mar the identity of an individual and result in a self stigma. Children from St. John's Leprosy Colony participate in the local community, specifically at Gnanodaya School. If anywhere, it would be thought that the stigma of association would be experienced at school as peers from the local community are aware of the children's background. From the interviews conducted with the children at Gnanodaya School, children initially expressed embarrassment and shame when their parents would visit them (boarders) as local children would ask question about their parent's deformities. However, over time, a level of acceptance has been established and visits from leprous family member no longer appear to stir up discomfort and shame. Due to the atmosphere created at Gnanodaya, a relatively low level of stigma by association appears to be experienced by the children. Thus, self stigmatization appears to be absent within the schooling context.

Within the home, the stigma attached to one's identity is communicated. This communication need not be verbal but rather, these children are surrounded by examples of self stigmatization which is communicated through apathy, rejection of society, and in due course, a rejection of self. Children, although escaping the direct impacts of stigma, are surrounded by the results of discrimination. As noted by Gnanodaya principal, Mr. Thangaraj expressed that children from leprosy colonies generally suffer with a low self esteem. According to Mr. Thangaraj,

there is a lack of self esteem, children feel like they are inferior and not valued. In addition to education, emotional support is needed especially for the colony

children. These children need to receive affirmation and hear that they have value. Overtime the message begins to sink in and these children now have goals and dreams. I use to tell them, focus on education this is what will guarantee you a bright future. They see the situation of their families and they don't want the same future. I we remind them that education can free them from this – this alone serves as incentive to work hard.

Despite the prevalence of low self-esteem amongst school-going children, education is providing a way for children to reject self stigmatization as evidenced by the ambitions and hopes they have for their futures. Moreover, the growing trend of pursuing marriage beyond the confines of a colony, illustrates a weakening of self stigma that has previously limited the perceptions of what is achievable. It should be noted that this generation is achieving a level of integration not know to generations past. This integration is being cautiously affirmed by the older generations within the colony. There is an affirmation that increased integration creates economic opportunities that provide for both the children and their families. However, with a decreasing self stigma held by children, parents express a fear that children will mask their identities, marry an outsider, and sever their ties with the colony. Although integration is becoming more of a reality in the psyche of this generation, it appears that in order to achieve the full benefits of upward mobility, children must become foreigners to both society and to their families.

6.1.1 Misconceptions of Leprosy

The misconceptions of leprosy abound both in and outside the colony, feeding into the stigma and maintaining the barriers that have isolated those marked with the disease. The statements below illustrate the wide-ranging perceptions of leprosy, present both in and outside the colony:

I am not exactly sure. I believe that the disease came to them because of their forefather's sin. (Middle aged woman waiting for her children at a shop)

The disease can be contracted for two reasons, but mainly because of worrying. When you worry you will get the disease. Secondly, it is also passed down through generations. (Young man at train station)

We don't know how....there are many different understandings. Some of us believe that we get it because of the sins committed by our forefathers, some say it's because of bacteria...there are so many different beliefs. (A healthy leprosy free colony member)

Some of us believe that God has cursed us – who knows why we carry this? (Female leprosy patient)

If a basic understanding is lacking, the presence of a fearful stigma becomes justified as fear is associated with what is unknown. The findings communicate that the majority of respondents believe that leprosy can be easily transmitted, automatically heightening the fear of the diseased. Thus, social isolation continues, being upheld by the lack of knowledge possessed by outsiders and additionally by the colony members' desire to avoid further rejection. Consequently, misconceptions of leprosy continue to strengthen the barriers that exist, reinforcing a social isolation of those from leprosy backgrounds.

Society's fear and repulsion of leprosy is communicated chiefly toward the sufferers. Yet the effects of acting upon these fears and stigmatizing the sufferers is seen in individuals one to two generations removed from the disease. However, the effects do lessen in successive generations. The data shows that children from the colony experience a comparatively low level of stigma. One way in which this can be measured is by the increasing ability to integrate into society. The colony children's future appears bright, holding opportunities not known to the grandparents or parents generation. Whereas in the past, access to education was a gamble, now it is presently being secured. Where integration with the broader community was once barred, it is now occurring. Despite the low to no level of education present among the older generation, there is hope that the children will be educated and secure good jobs.

Most adults were unsure of their own futures, but a strong concern and interest was communicated in regards to their children's futures.

6.2 Securing an Education

From the data, it is evident that physical access to education is available to children from St. John's Leprosy Colony with three schools established within a 5 kilometre radius. Further, education at these schools has been secured which is shown by the present enrollment rate of the colony children, with 40 of 40 children currently enrolled in school. The enrollment rate illustrates that education is accessible and secured. However, the research findings suggest that the process of securing education needs to be examined in order to understand how this access is obtained.

Resistance and denial was initially encountered when seeking to secure education for the children of St. John's Leprosy Colony in both local and government schools. These children were denied a place on the grounds that they were from a leprosy colony. The teachers at the government schools expressed that "if you admit these children in our school, the parents from this community will no longer send their children here...we cannot accept these children." Although unconstitutional, the children from the colony were denied enrollment with the teachers advising the parents to not return. From the findings we know that the families seeking admission for their children were new to the community and speculation and fear about the colony members existed. Furthermore, not just one child was seeking admission, but rather the children of the entire transplanted colony's members. Enrolling the colony children proved to be too great of a risk for the school to take. Mr. G.R Srinivasan of the Swiss Emmaus Leprosy Relief Work comments on the situation saying that:

even though the picture is changing, problems [are] encountered especially if the parent seeking admission for the child had physical deformities. The problem lays not so much with the children, but with who they are connected to....if the child is seen with the person with deformities, then rejection based in fear will be likely to occur.

In response to the problem encountered, Gnanodaya, a school catering to children from both leprosy and non-leprosy backgrounds was birthed. Ahkilesh, co-director of National Leprosy Relief and Rehabilitation Work (NLRRW), states that more and more education can be obtained, but more often than not, “there is still a need for an in-between. If there is no one acting as an in-between, education would be very, very tough to secure...the stigma is still very present.” Even though the children from St. John’s Colony are free from all signs of the disease, they continue to be identified as children from leprosy background, thus instilling fear. Therefore, Gnanodaya represents that so called ‘in between’ in helping children from the colony secure education.

6.2.1 A Valued Education

...at the village level the parents [from leprosy colonies] concern is money...it is a pressing need and they need it immediately, education on the other hand is not as important.

V Sreenivasulu from Gremaltes

From the NGO’s and government organizations interviewed, living in a leprosy colony appears to be intimately linked to poverty within the Indian context. Leprosy colonies, cut off from free access to economic integration, generally find themselves living in impoverished conditions. St John’s Leprosy Colony, a comparatively fortunate colony owes its relative stability to what Mr Gopal notes as “strong leadership within the colony and a steady flow of outside funding.” However, despite the relatively positive conditions of the colony, the need of money remains.

Securing money becomes a necessity and urgency, particularly for the leprosy patients who are unable to secure jobs.

As suggested above by Mr. Sreenivasulu, in situations of poverty, money is the felt need and ideals such as education become secondary, as they are viewed as extra luxuries and not valued. This however does not appear to be the case for the families from St John's Leprosy Colony. Although money is a need and poverty is closely associated to the disease, the choices of individuals from the colony stand in contradiction with this stereotype. Firstly, the request for the building of Gnanodaya School communicates an awareness of the value of education. Secondly, sacrifices to prioritize education have been made, contradicting the belief that education is not valued. Mr Gopal of IDEA India states that:

Education is valued. You see the trend of the general population... they want to educate their children because they see the benefits of education... Parents from leprosy colonies see that regular children are getting high salaries, so they begin to ask, why not our children? So everybody now values education – it has not always been this way, it has shifted in the last 10 years. But please note that I am talking about Tamil Nadu, in the north it is not so. In the north access to schools is hard...even though there is more stigma in the south. Historically, South India has had a higher concentration of leprosy patients which has created a higher level of opposition and fear towards the sufferer.

Another indicator that illustrates the priority given to education can be seen through the lack of children found begging in St. John's Colony. Those suffering from the physical deformities of the disease find themselves facing a void of employment opportunities and are left with no other choice but to beg. The meagre monthly Rs. 400/- government pension allocated for leprosy sufferers²⁰ only covers a fraction of their actual expenses, making begging a necessity. Begging provides money but according to the respondents in the colony, it is not a desired way of gaining income because it strips them of dignity as they daily plead for money,

²⁰ 'Leprosy Sufferers' refers to those who have severe disfigurement and ulcers.

begging passerby's for a handout. In St. John's Leprosy Colony a firm understanding of what education can provide exists and there is a notable opposition to the idea of children begging. In St. John's Leprosy Colony, there are no known cases of children begging despite the income that they could generate. Mr. Gopal explains that child begging happens among the poor children, but rarely among poor children from leprosy backgrounds.

...see the reason behind this is leprosy affected people have been forced to beg, they don't want to, their physical deformities leave them with no other option, but even though they have no choice, they do not want their children to beg, to become like them. They know that they can have a choice.

Mr. Gopal suggest that the poor have a choice and begging is not the only option. The poor do fall into extremely difficult circumstances but despite this, jobs are available. For the leprous individual, the luxury of choice is nonexistence and they are forced into begging by the presence of their deformities. Yet, despite the lack of personal choice, they choose to shield their children and grandchildren from this occupation. Regardless of the financial struggles that arise, families from leprosy backgrounds, particularly in St. John's Colony, are seen resisting the easy solution of begging and making sacrifices to send their children to school, clearly demonstrating that education is in fact valued.

6.2.2 An Integrated Education

The research findings show that within the first year of functioning, the makeup of Gnanodaya School consisted solely of children from leprous backgrounds. However, with time, the inhabitants from Venkatapuram began to enroll their children in the school as securing education began to take precedence over the fear of integration that initially existed. After the enrollment of one child, the community's children began to trickle in and the fear in the community lessened. Although when the children from the community developed any illness, (i.e. common cold or fever.)

parents were fearful that it was leprosy connected and the children from leprosy backgrounds were quickly blamed.

It is significant to note that after 2 – 3 years of Gnanodaya's establishment, the same government school along with private schools in the area which once denied education to the colony children, began to accept these children in their schools. It appears that the establishment of one outspokenly integrated school led to other schools slowly beginning to integrate their classrooms. Although children from the colony represent the minority in the private and government school, it should be recognized that the schools are beginning to knowingly accept leprosy colony children. From this finite study, we can observe a gradual move towards integrated education.

The integration in education that is occurring is encouraging. However, the influencing factors that might serve as a catalyst in the accepted integration of Gnanodaya School should be considered. As previously mentioned, the community of Venkatapuram consists of individuals securing low wage, labour intensive jobs. The local area is comprised of individuals that are predominantly uneducated and belong to the scheduled caste with a lack of economic stability. Gnanodaya, offering an education free of cost until the 10th standard becomes an alluring offer despite the fears that exist in regards to integrated education. Thus, it should be considered whether the integration of Gnanodaya School is occurring due to a shifting in society's perceptions or due to the shared need for education amongst the children of the local community and the leprosy colony.

Despite the progress noted, blanket assumptions cannot be made that colony children are free from the stigma attached to the disease. Beyond the visible level of integration (i.e. education) lie beliefs and attitudes laden with fear and opposition. Education to a degree is a controlled level of integration and separation can still be maintained, however, topics pertaining to a more intimate level of social integration, (i.e. sharing of food, marriage) revealed a marked level of opposition disclosing the core sentiments towards those from leprosy backgrounds. Therefore, the findings

illustrate various other indicators of stigma exist, such as the topic of marriage which has been briefly considered.

6.3 Education: A Vehicle to Escape Stigma?

For the children of St. John's Leprosy Colony, it can be said that education is providing the tools to succeed that have been absent or limitedly accessed before. However, will this ability to secure education lead to a life free from stigma and open doors of opportunity previously unknown to colony members? From the findings of this study, one can conclude that yes, new opportunities will present themselves based on the education secured, yet it is unlikely that the educational credentials will equate to a life free from stigma.

Although the research's focus was not directed towards the situation of the children post education, additional information pertaining to this topic was gathered. According to Mr. Gopal, the area where young adults from leprosy background most clearly face limitations created by stigma is in "their opportunities to secure good jobs, establish economic security and in marriage." As seen, jobs have been secured, but the majority of the colony members are working in labour intensive, low paying jobs or accessing jobs provided to them through DIK. The general trend to obtain menial labour jobs is commented on by Mr. Sreenivasulu from GREMALTES stating,

if they get a job it will be only a small job, earning little and it amounts to nothing that aids in instilling worth...so this is the problem. On the one side the youth experience psychological problems and on the other side are the economical problems they encounter, serving them a double hit.

Securing strong employment works to alleviate the economic stress and instills hope and worth in the individuals. Securing decent jobs in the colony is slowly increasing, especially when there is assistance provided from outside organizations (i.e. DIK) to serve as an in-between. Young adults are growing more able to secure

jobs due to the increasing levels of society's acceptance and due to the ability to mask their identity in the process of securing jobs.

However, in regards to marriage, hiding ones connection to the colony becomes increasingly difficult. If marital alliances are established outside of the colony they typically happen because: 1) A young adult leaves, cutting off their ties with the colony or 2) A colony member seeks a spouse outside the colony without disclosing where they are from. Mr. Gopal states that:

the place where stigma runs deepest is in marriage. Sometimes you will observe that the affected person will 'disappear' in order to secure a marital alliance with someone from the outside. As long as the individual is associated with the colony...outside society will not accept integrated marital alliances.

If the identity of a colony individual attempting to secure a marriage with an individual from a local community is exposed, the chances of a union are extremely low. Gopal relayed a story of a boy from a colony in Chennai who experienced the bleak outlook of an integrated marriage.

A leprosy affected man living in a colony in Chennai had a son who was free of leprosy and had successfully secured a job as a chartered accountant earning a good salary. In 2005, the father started to look for suitable girls as he desired to marry off his son. He submitted an advertisement in matrimonial section of the local newspaper.²¹ After the advertisement was published he received 140 interested responses. The father responded to all 140 applicants providing additional information on his son and communicated that the boy was living with his family and his father who was affected by leprosy. After this information was sent out only 10 people responded. All 10 girls and their families were given a formal invitation to come meet the boy. However, after all 10 of the girls and their families visited the house, they informed the father that they were no longer interested.

²¹ Placing matrimonial classified ads in newspapers is a common practice among Indian families attempting to secure a suitable mate for their child.

If a marriage is secured outside the colony, it most likely occurs when a boy disappears and leaves behind his family, severing his ties with colony to secure a bride and a new life. Such behaviour is looked down upon within the colony and is seen by parents and grandparents as dishonouring and ungrateful. A mother in the community voices that, “we support our children, it is their responsibility to remain and help us. Besides, a marriage to an outsider will not work, they do not understand us. The colony is the child’s place to belong.”

Although not as common, there are increasing accounts of young adults masking their true identities before a love marriage is officiated to secure a bride from outside the colony. An account of such an incident is seen in the following interview with Preeti, now a member of St. John’s Leprosy Colony through marriage. This case is unique as the boy brought his bride to St. John’s Leprosy Colony, maintaining his ties with the colony. However, as a result, Preeti association to her birth community was jeopardized due to the knowledge that she now lived within a leprosy colony. The interview was conducted at her house, and the informant (P), described to me, the interviewer (I), the adjustment that has had to be made to this life she was unaware of.

P: My husband's name is Ranjit Shaker from this colony. He was born and brought up here in the colony.

I: Are you from a colony in Tamil Nadu?

P: No, I'm not from a leprosy background. You see my husband's grandfather is originally from Salem, the place I am from. When he died, the funeral was held there and my husband came to attend the funeral— this is where we met. It wasn't long after that we wanted a love marriage. From the time I saw him to the time we married only one month had passed. The problem was he didn't ever tell me the truth behind where he was from. Only after I married him did I come to find out that he lived in a leprosy colony. When I arrived here I was shocked! I had never seen a place with people like this before. I was scared and afraid, afraid that I would catch this disease. For the first week that I lived here I didn't speak a word

to my husband. I didn't tell my family but after 4 months they found out and my relatives refused to come visit me.

I: Do you think you will stay here for the rest of your life, or is there an alternative?

P: I will have to stay here, stay with my husband, my baby, and now I have to care for my husband's grandmother as she is a leprosy patient. This is my duty.

I: What are the differences coming from a normal life into colony life?

P: My life was simple before – I could go anywhere and eat what I wanted without fear. But now I am scared, scared to go out, scared to eat – what if I catch this disease? I am okay going outside as most people don't know I am from this colony yet. My past life was good – there was freedom. If I knew what I was marrying into I would have never have married him.

I: Do you hope to leave one day?

P: Yes, I would like to leave. I have so much fear, and I am depressed. On my birthday I couldn't manage anymore and I drank poison. This was the first failed suicide attempt of two...this life is not what I wanted.

Within India, identity and belonging are strongly tied to family. This component of loyalty to family found in the Indian culture is mirrored within St. John's Leprosy Colony. However, within the colony a seemingly heavier weight is attributed to the notion of loyalty and belonging. In the colony, family obligations and roles are clearly defined. This is illustrated through Preeti's newly assumed role of a wife which in turn translates into caregiver of the leprosy affected in her new home. Although having no ties to the disease up until recently, Preeti now considers this new life as her future affirming the responsibility that is tied into the Indian family structure. Escaping the situation through divorce or by returning to one's parents is unheard of. Suicide apparently stands as the only option. Thus we generally see that loyalty to family takes precedence over attempting to escape the association with the disease even if one's identity becomes negatively impacted. This perhaps uncovers the deep levels of stigma and opposition attached to an intimate social integration. When a marriage occurs between a leprosy free colony member

and an outsider, a union to the colony and the disease occurs and the spouse's identity takes shape around their new family.

In conclusion, this chapter has given an analysis of the research findings and shown that education is being access for the children from the colony; however, securing educational credentials does not erase the harmful impacts of stigma. Various indicators of stigma surface in spite of the fact that the children have obtained an education. Examples of arenas in which stigma prevail despite the education accolades secured are in marriage and economic integration.



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CHAPTER VII

CONCLUSION

In the concluding chapter, the uniqueness of the specific case study will be considered while additional factors that were not given primary focus in the research will be mentioned. Additional research questions raised through the findings will be briefly considered, and the overall findings of this study will be recapped and summarized. Lastly, suggestions will be made in regards to strengthening this study.

The exceptional nature of the case study should be acknowledged as the results of this study do not necessarily correlate with the standard set norms of children growing up in leprosy colonies. The research findings for this study gathered data from two locations that are relatively new in the geographical location of Venkatapuram. Because both St. John's Colony and Gnanodaya have a relatively short history, the data gathered was recent and as a result of the experimental stages of adjusting to the new location. Furthermore, the case study of Gnanodaya School and St. John's Leprosy Colony proves to be exceptional due to the financial contributions of an outside donor (DIK). This dependable income creates a situation that does not necessarily represent the norm for children growing up in a leprosy colony.

Due to the exceptional nature of both St. John's Leprosy Colony and Gnanodaya, the data gathered revealed information that illustrates the uniqueness of this case study. The results of this study limit the ability to use the information in forming accurate analysis and conclusion for the situation for children in other colonies in Tamil Nadu. In short, more research in a number of Tamil Nadu's colonies is needed in order to use the information obtained to offer broadly applicable suggestions. However, this case study also provides hope and optimism as it demonstrates the change that is occurring and the progressive initiatives that are being implemented (i.e. Gnanodaya School) in the village of Venkatapuram.

7.1 Additional Contributing Factors

This study reveals that the challenges in securing education is not shaped by one sole, static factor. Rather, there are a variety of dynamic factors that contribute to the conditions and challenges faced by these children. The stigma of leprosy, as we have seen, plays a significant role in the formation of identity; the process of accessing social services; interactions with society; and in the future outlook of children from the colony. However, stigma is not the exclusive cause that creates barriers and challenges for children from leprosy colonies. In regards to the colony children's access to education, challenges beyond stigma exist, with economics, and class/caste being two strong factors that lead to the creation of additional barriers.

As previously noted, a strong link exists between poverty and leprosy. Despite the financial support of DIK, the residents of St. John's Leprosy Colony still experience levels of poverty. Education has been secured largely due to the specific creation of Gnanodaya School which assists colony children in their attempt to secure education. However, education has also been secured due to the financial scholarships and support that is provided to these children. Without the financial support from DIK, it can be proposed that the enrollment rate of St. John's Leprosy Colony would significantly decrease. Further, the impacts of caste/class cannot be divorced from the topic, as leprosy children, stigmatized by the disease, poverty, and their outcast status, face obstacles in securing education both as a result of these various stigmas and the limitations created by caste/class.

7.2 Further Considerations

From the information gathered through this study, additional questions have surfaced. Although pertaining to the future of the colonies, these questions are useful to consider as they directly impact the futures of the children living within the colony. Below, two of the topics will be considered.

7.2.1 Leprosy Colonies in Transition

As illustrated through St. John's Leprosy Colony, leprosy colonies are in transition. This transition might appear sluggish or nonexistent particularly when considering that leprosy remains a disease of the poor and is still strongly linked to stigma. However, significant strides have been made and the face of leprosy is changing. For the last 13 years, India has had access to a free cure for leprosy (MDT). Due to this cure, centuries of misconceptions are gradually being addressed. With the majority of the sufferers being cured and leprosy case detection at its best, India's ties to the disease are weakening. Presently, the dominant population within colonies is made up of leprosy free individuals. Further, the bulk of the sufferers are aged and this disease will in effect die out and be extinct within the next 15 – 20 years.

India continues to address the social burden that remains. The country has witnessed a medical transformation and more recently, the country is beginning to see a modification to the social components of the disease. Work to implement change within the social situation is largely being spearheaded by NGO's. The children presently growing up in the colony will grow up alongside a dying disease that is carrying a slowly diminishing stigma. Children who are the future of the colony are accessing social services to a degree not experienced before. Education, one of the services being accessed, gives these children the opportunity to one day secure good jobs and potentially break the chain of poverty known to their family for generations.

Standing in the midst of such a drastic transition, one must consider the future of these colonies. With the increasing integrated opportunities for children, will the correlation between leprosy colonies and poverty end? Will the physical construct of leprosy colonies continue after the sufferers have passed away? Will the stigma of association live on? Or, will the death of the generation of leprosy sufferers lead to the death of leprosy's stigma?

7.2.2 The Role of the In-Between

The findings have shown that the situation for individuals living in St. John's Leprosy Colony is becoming increasingly hopefully. A growing integration with the wider society can be seen in social participation, education, and employment. Yet, upon deeper inspection it becomes evident that this integration has not been self created but rather, it has been made possible and coaxed into existence by organizations and individuals posing as in-betweens. The role of the in-between, largely played by NGO's is intimately tied to the increasing levels of integration and as a result, the increasing levels of success seen in these colonies.

NGO's do play an important role in the advancement of leprosy colonies, as seen with DIK's role in St. John's Leprosy Colony. Posing as in-betweens, NGO's are able to secure opportunities for members in the colony. However, one should consider the sustainability of NGO's. What happens to a colony when an NGO's funding is depleted, when an NGO relocates or changes its focus? Would it be possible to suggest a more permanent organization to serve as an in-between for these colonies? What is the role of the Indian government in supporting leprosy colonies?

7.3 Summary

Through the data collection and analysis, this study reveals that the condition of the children growing up in St. John's Leprosy Colony has improved from generations past, yet limitations created by the stigma remain. The research shows that education has been secured by the children but the process of securing education does not stand independent from the impacts of stigma. Education does in fact provide these children with a stronger possibility of obtaining good employment which could potentially aid in escaping the economic hardships faced in the colony. Nevertheless, education does not do away with the stigma of association that links these children to the colony, and ultimately, to the disease. The study has shown that access to education has provided the children with a hopeful platform to propel them beyond the opportunities known by generations past. The study also reveals that

although education has provided hope, it is not a ticket to complete success as various limitations created by stigma, and independent of stigma, remain.

7.4 Future Research

This study has uncovered a finite facet of the situation for children growing up in a leprosy colony. There are a multiple other angles that need to be explored in order to build a holistic understanding of the challenges and hurdles that are encountered by these children. Nevertheless, from the research exposed through this study, it is hopeful to note the shift occurring in society's perception of these children and to observe an increasing integration of children into the education system. Carrying out research to study the situation of the colony children after completing education would be beneficial, and serve as an indicator to measure the value and necessity of securing education for children from leprosy colonies.



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APPENDIX A

ศูนย์วิทยทรัพยากร
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Photo A.1 Gnanodaya School



Photo A.2 Children in the 3rd standard classroom at Gnanodaya

BIOGRAPHY

Ana Svoboda, originally from the United States, spent the first 18 years of her life with her family in Chennai, India. After graduating in 2000 from Hebron School in Udthagamandalam, South India she went on to pursue a BA at Eastern University, Pennsylvania, United States.

Upon completion of her BA degree Ana spent a year volunteering with a Christian organization, which was based in South Africa, Kenya, and Tanzania. Shortly after, Ana returned to Chennai, India and began working with National Leprosy Relief and Rehabilitation Work. Ana joined NLRRW as the project manager for an agriculture and nutrition project being implemented in three leprosy colonies.

Growing up on the 'field' coupled with her work and volunteer experiences led her to pursue a MA degree in International Development through Chulalongkorn in 2007-2008. After graduation Ana intends to continue working in the development sector with a specific focus on poverty, women, and children.



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