System of Service Delivery for People with Disabilities in India and Impact in Rural Areas

21

Amy D. Spriggs, Elizabeth Siereveld, Molly Baldridge, Kaylee Ortiz, and Thomas Young

Overview

India is one of the oldest civilizations in the world, dating back to 2500 BC (Allchin & Allchin, 1993). Geographically, it is the seventh largest country in the world lying entirely in the Northern Hemisphere. India stands apart from the rest of Asia with its borders marked by mountain ranges in the north and by the sea in the south to give it its own distinct geographical ethnicity. India's total population is 1,210,569,573, making it the second largest country in the world (India Register General and Census Commissioner, 2011). India is a culturally rich and diverse country with many factors contributing to the unique views on family, spirituality, and differences.

Given the size of India and the diversity found within and between geographical regions, this chapter will not cover the totality of disability or rehabilitation in the country. Rather, this chapter will focus on experiences in the state of Karnataka

in southwest India, an area the authors of the chapter have spent time. Karnataka is the eighth largest state by area and ninth largest state in population; it is made up of 30 districts, 176 subdistricts (taluks), 347 towns, and 29,340 villages. The census data from 2011 lists the population of Karnataka at 61,095,297. Bangalore, the state capital, is the most populated district which accounts for 15.75 % of the state's total population (India Register General and Census Commissioner, 2011).

Karnataka is one of the prominent states in all of the country in terms of economic development. Karnataka tops India in biotechnology, a leading industry in the state. Bangalore is often referred to as the "Silicon Valley" of India because of its large focus on business and innovation (Byker & Austin, 2014). Although the large cities like Bangalore are considered world leaders in manufacturing, the majority of the workforce is engaged in farming-related activities. This is especially true in the smaller rural villages located around the state (Planning and Statistics Department, 2006).

Mayasandra, a large farming village located in Turuvekere of Tumkur District, Karnataka, includes 925 families. Mayasandra has a total population of 3778 residents based on the 2011 census. The village has a higher literacy rate than the state of Karnataka (i.e., 87.31% in Mayasandra compared to 75.36% in Karnataka). Males have a literacy rate of 92.45 % compared to 82.29 % of females (Census Population, 2015). Mayasandra's

A.D. Spriggs (✉)
Associate Professor of Special Education, University of Kentucky, Lexington, KY, USA
e-mail: amy.spriggs@uky.edu

E. Siereveld • M. Baldridge • K. Ortiz
University of Kentucky, Lexington, KY, USA

T. Young
Jim & Suzanne Elliott & Family Professor of Pediatrics, Kentucky Clinic L449, University of Kentucky, Lexington, KY, USA

staple crops are rice and coconuts, which are common for many rural villages in the southern part of India due largely to the climate. Along with rice and coconuts, farmers grow many fruits and vegetables, including potatoes, beans, lettuce, bananas, and oranges. Many of these crops are sold within the village, but some are sold in Northern India, where the climate is more suited for growing coffees and teas. In addition to farming, many women from the village work as tailors or storekeepers; some find work on a local flower farm, which exports their goods to shops in Bangalore.

Traditional Cultural Values and Strengths

India's culture is shaped by social class, family, and spirituality, which have been greatly valued throughout history. All of these work together to inform cultural traditions and rituals observed by many. This is largely defined by beliefs and values dominant in the country and its people. The uniqueness of Indian culture lies in its strong caste (social) system and individual family values. The caste system is a system of ranking people by their jobs and ritual status (Jacobson, 2007; Llewellyn, 2015). Historically, there are four castes that people belong to: priests, warriors, merchants, and servants. Recently, "government census and anthropological surveys have identified hundreds [of castes] in South Asia" (Llewellyn, 2015, p. 78). This caste system is a structure people are born into, marry within, and continue to live within while on earth. Family structure and spirituality are both impacted by this system.

Family In India, family has been the foundation for everything else for many generations (Mullatti, 1995). India is considered a collective society, putting things such as family honor, dependability, and unity before individual needs (Hui & Triandis, 1986). Families are often found living in the same geographic region, with up to three or four generations living in the same home (Chekki, 1996). This is especially true in the more rural areas, where farming is common (Niranjan, Nair, & Roy, 2005). Younger generations are faced with

taking care of elders, as well as those with disabilities. In this model, life decisions for things like career choice or marriage partner are made jointly with the family (Mines, 1988).

Males and females raised in Indian families experience these family values in different ways (Ram, Strohschein, & Gaur, 2014). Although several family structures exist (e.g., joint, nuclear), in many places in India, the eldest man still working in the home is typically in charge of the home. Boys and girls are raised the same throughout early adolescence. As young adults, boys will often attend college and marry after graduation; when they move back into their parent's home, they will often assume the role as head of the household, and their father will retire. Girls, on the other hand, are more often married by their late teens or early 20s. They will move into the home of their husband and his family.

Several possible factors may explain this family adhesion, especially in rural areas of India. Many have speculated that social class and religious beliefs play a large part in this (Mines, 1988; Williams, 2013). It is common for parents to arrange marriages for their children within the same social class (Mines, 1988). Many living in India also have a strong belief in karma and dharma that tie into the repeating cycle of life. The principles of karma and dharma include treating others with the highest dignity and respect because what goes around comes around (Tiwari & Pandey, 2013). This translates into the belief that parents who support their children will raise children who will support them when it is needed. Although these two factors certainly exist within many families, Niranjan et al. (2005) found that socioeconomic status, land ownership, and age and education of the head of the household were more indicative of specific family structures. For those living in rural India, joint families are more likely to live with extended family.

Spirituality India is made up of groups belonging to different races and religions where people who practice different religions can coexist while living next to each other. Many villages, such as Mayasandra, have two predominant religions: Hinduism and Islam. The villagers practice their

religions separately but live together in harmony. About 80 % of the people living in India, and Mayasandra, practice Hinduism; 13.4 % practice Islam (Anees, 2015).

India is often identified as the birthplace of Hinduism (Lorenzen, 2016). Hinduism has many different variations and is made up of several sects (Doniger et al., 2016). Hinduism is believed to be a pathway to a strong connection to God, as God is everywhere and in everything. Temples decorated by various gods and goddesses can be found all over India. The most common gods include: Brahma, Vishnu, Shiva, and Devi (Jacobson, 2007; Lorenzen, 2016). Hinduism is linked to the caste system. People working in a lower caste believe that religious purity can alter the caste system they are reborn into (Jacobson, 2007; Llewellyn, 2015). This purity is extended into other areas of a Hindu's life. For example, people avoid contact with body fluids, feet, the left hand, and often members of different castes (Llewellyn, 2015). Body fluids such as blood and saliva are thought to be pollutants, feet are considered impure, and the left hand is viewed as unclean. The hand preference is commonly observed because the right hand is used for eating, and the left hand is typically used for bathroom purposes. Purity and pollution influence social groups and their interactions (Henderson, 2002).

Islam, the religion practiced by the Muslim community, is the second most common religion practiced in India (Anees, 2015; Williams, 2013). Hinduism evolved gradually as a way of life, while Islam was founded by the Prophet Muhammad (Doniger et al., 2016; Schimmel, Rahman, & Mahdi, 2016). Muslims believe all people are created by God, and God's will influences both destiny and fate. They believe that there is divine intention and order in the universe; that is, everything is created to function independently, but under the direction of God. They also believe they are called (by God) to help those in need, which leads to a strong sense of community among various families (Schimmel et al., 2016).

Views on Differences Although there is a strong sense of family unity and a deep sense of spirituality for many living in India, these two factors can negatively impact views on differences, especially if those differences include disabilities. For those who believe in karma, a disability is often seen as a punishment for things done in a previous life (Singh, 2000). The punishment is meant to be something a person must go through to get to a better place in their next life, so others often do not intervene. This has led to decades of no services for individuals with disabilities. Many believe that along with karma, disabilities can be passed from one person to another or from one generation to another. Therefore, some people with disabilities in India are hidden because they can cause social and physical burdens on their families and caregivers (Janardhana, Muralidhar, Naidu, & Raghevendra, 2015). For example, many marriages in India are arranged, leading to hiding family members with disabilities because their siblings will not be able to find suitable marriage partners. Before an arranged marriage can take place, both families have to agree that the marriage is suitable. Many believe that if a child in the family has a disability, future generations will also have a disability (Janardhana et al., 2015).

Although the views on differences still exist, there is a growing trend toward acceptance for those with disabilities. There are services available in many large urban cities for those that can afford them. However, most people with disabilities live in rural areas of India making it hard for them to receive the services that they need.

Rate of Disability

According to the 2001 Indian census, 2.13 % (i.e., approximately 21 million people) of the population in India is considered disabled (Chavan & Rozatkar, 2014). The census is based on data that can be subjective, so that number has been estimated to be as high as 6–8 % (i.e., as many as 70–90 million people; Anees, 2014; Janardhana et al., 2015). Seventy-five percent of these individuals live in rural areas, and only 49 % are literate (Anees, 2014). Disabled classifications include sight, hearing, mental, physical, and speech disabilities (Ministry of Statistics and Program Implementation, 2011). The Indian government

has realized that the mind-sets of its people need to change, and they need to begin accepting individuals with disabilities. Thus, several government task forces and committees have started providing services and making more places accessible for persons with disabilities. This process is slow, but the change has started and will continue to grow and progress as citizens in India begin to accept differences on a more global level.

The Integrated Education for Disabled Children (IEDC) was passed in 1974. It was one of the first initiatives to improve education through integration and inclusion for individuals with disabilities (Sharma & Deppeler, 2005). In 1986, The National Policy on Education promoted inclusion with a goal to integrate "the handicapped" in all aspects of the community (Singal, 2006). A program that the Government of India funded, the District Primary Education Project (DPEP), was founded in 1994 to integrate individuals with mild to moderate disabilities in schools. In 1996, the Persons with Disabilities Act (PWDA) was passed to mandate this integration (Sharma & Deppeler, 2005). The PWDA was put into effect because of the lack of resources individuals with disabilities had in India. It provided legislation that required non-discrimination, producing more accessibility to education, employment, buildings, transportation, and communication. The Sarva Shiksha Abhiyan (SSA) is a policy of zero reject that was put into effect in 2001. It mandated that no child could be denied education due to their disabilities. IEDC was revised in 2009 and is now known as Inclusive Education of the Disabled at the Secondary Stage, which allows an individual to enroll in 4 additional years in an inclusive setting after the completion of their 8-year elementary schooling (Ministry of Statistics and Program Implementation, 2011; Sharma & Das, 2015).

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which India is a signatory under Article 9, requires governments to ensure accessibility to information, transportation, physical environment, communication technology, and accessibility to services and emergency services. The Indian government has a vision of an inclusive society in which equal opportunities and access are provided for growth and development of persons with disabilities to lead productive, safe, and dignified lives. This initiative by the Ministry of Social Justice and Empowerment conceptualized the "Accessible India Campaign" as a nationwide flagship campaign for achieving universal accessibility that will eventually enable persons with disabilities to gain access to equal opportunities, live independently, and participate fully in all aspects of life within an inclusive society. It has been mandated that by 2019, 50 % of all government buildings in major cities in India are to be accessible to all individuals, regardless of disability, by a collective effort by all government agencies.

The Biwako Millennium Framework was created by the Economic and Social Commission for Asia and the Pacific (ESCAP) in 2002. This was a framework for action, which was produced in an attempt to promote inclusion and rights for individuals with disabilities in the twenty-first century. The framework was made up of a series of targets, which focused on organizations of persons with disabilities and related family and parent associations; women with disabilities; early detection; early intervention and education; training and employment (including self-employment); access to buildings and public transport; access to information and communications, including information and communications; and assistive technologies (Ministry of Statistics and Program Implementation, 2011).

System of Service Delivery

Although the idea of inclusion of students with disabilities has been accepted on many levels, the subject still proves to be a topic of great controversy, especially in developing countries. In recent years though, many Asian countries have begun to embrace the idea of integration and inclusion within their schools. In India specifically, its national government has enacted a number of initiatives in order to promote integration and inclusion of children with disabilities including IEDC, 1974; Project Integrated Education of the Disabled (PIED), 1987; and PWDA, 1996

(Sharma & Das, 2015). The PWDA is much like the legislation in the United States passed in 1975 as it could impact the access to education for millions of children with disabilities. However, when looking at the effect of this system of delivery, one must consider the great demographic divide between India's urban and rural areas, specifically the differing incomes and resources. Throughout India's history, as in most developing countries, the incidence of poverty is higher in rural areas than in urban areas. As India has continued to develop, the gap between rural and urban areas has continued to grow. For example, in the 1960s the ratio of the rural poverty rate to the urban poverty rate in India fell within the range of 1:1–1:2, but in the 1990s the ratio leaped to 1:4 (Datt & Ravallion, 2002). In an epidemiological study of child and adolescent psychiatric disorders in various areas of Bangalore, it was found that there were no significant differences between prevalence of disabilities in rural versus urban areas (Srinath et al., 2005). The prevalence of disabilities tends to be the same in both rural and urban areas. However, due to the division of resources, those living with disabilities in rural areas do not have the same access to the supportive services found in urban areas. Therefore, in order to discuss service delivery, the context in which it is delivered must be considered.

While the delivery of services for those with disabilities in India may look different from that of Western cultures, it is still happening in one form or another. For example, within Bangalore, a major urban area, there are several segregated support schools for those with disabilities. One organization in particular, the Spastics Society of Karnataka (n.d.), was founded with the goal of, "conscious, conscientious and constant endeavor in maximizing the potential of children with special needs Inclusiveness in all aspects of daily life," as well as, "establishing their rights to be part of the community." Some other organizations include Apoorva Center for Autism, Autism Society of India, and Communication DEALL. These programs most often serve a specific population of children, they can be expensive for families, and acceptance into the programs can be difficult. In addition, children with more severe disabilities

can often be disregarded when considering admission into programs. For example, Beautiful Gates Special School in Mysore, India, states in their admission policy:

> From time to time there may be applicants who would require extraordinary attention that would reduce the resources available to other students or that may pose a potential risk to other students. Beautiful Gate Special School must consider the best interest of all its students and, therefore, reserves the right to not accept such applicants or dismiss such students (n.d.).

Outside of these larger organizations, service delivery is funneled through smaller programs, funded by nonprofit organizations, without involvement or resources from the government. This is typical for service delivery in rural areas in India (Singal, 2006). For example, Nava Nirmana Charitable Trust (NNCT) in the village of Mayasandra is a small segregated school funded by several organizations, including the Rotary Club of India. Although these segregated schools are positively impacting the rural communities, the lack of funding and available resources does impact the amount of intervention that can be implemented. For example, within the Spastics Society and many other large organizations in urban Bangalore, staff are trained, and students are given access to many resources, including wheelchairs, walkers, therapy and sensory materials, assistive technology, and adapted curriculum. Within the rural areas, teachers have no access to training. Specifically within NNCT, only two walkers are available, there are no wheelchairs (nor would they be accepted), and physical therapy is done with a mat and stander. A curriculum is not available for the students and/or teachers, although they do pay to receive advice from a larger organization (e.g., Spastics Society of Karnataka, Communication DEALL) once a month.

Once individuals with disabilities become adults, options for rehabilitation services are rare. The Spastics Society of Karnataka offers follow-up programs for those with disabilities if they are unable to be mainstreamed at the secondary level, including community-based rehabilitation, where the adults with disabilities are provided the opportunity of working in a "sheltered workshop"

where they learn the skills needed to make materials that are income generative. These items can include bags, clothes, wallets, trinkets, etc. Overall, few programs exist for those with disabilities that have exceeded the age limit of special education services. Much of that may be attributed to the many cultural barriers that prohibit those with disabilities the opportunity to become an active member in India's society.

Discussion Box 21.1

Mayasandra is a large farming village that grows crops like rice, coconuts, fruits, and vegetables. There are many jobs that can be created from these farming activities. Some examples include planting and cultivating the crops and selling the crops within the village. Although there are many jobs associated with the actual planting, harvesting, and selling, there are some other jobs that need to be created, so everyone can be productive during nonfarming seasons or droughts. Some jobs that are common to villages like Mayasandra include tailors, shopkeepers, and teachers.

Although the opportunity for various jobs exists in small villages, many times people with disabilities are not given the opportunity to have jobs. They are often left at home while their parents work if they are not in school. Many times those with disabilities are seen as burdens to the family. This can be because they cannot work independently or slow down the work of the rest of the family.

1 What are some jobs that could be completed by individuals with disabilities in regard to farming activities?
2 What are some jobs that could be created to be completed by individuals with disabilities when farming isn't possible?
3 How can the teachers at NNCT facilitate teaching job-related skills for the adolescents while they are still in school?
4 How can teachers and families work together to ensure the job skills taught are important, realistic, and sustainable?

Barriers to Service Delivery

As mentioned above, one barrier to service delivry is the demographic divide between India's urban and rural areas, but there are many more to be considered. Most of the barriers could fall into one of five categories: government, social, attitudinal, family, and access to services. Although India's government has initiatives in place to encourage education of those with disabilities, no laws currently mandate education for this population. India also does not have the funding or teaching power to enforce such laws (Hernandez, 2008). India's government acknowledges that not much of their national budget is devoted to educational expenditures. The country relies heavily on nongovernmental organizations to supplement basic education costs, yet they continue to struggle in providing the funds for universal education in an already limited budget (Hernandez, 2008). On top of lacking funds, India does not have teachers that have been appropriately trained or equipped to work with those who have disabilities (Hernandez, 2008). In addition, India lacks the support needed in classrooms to provide accommodations and individualized support, with the average class ratio being 1 teacher to 40 students (Hernandez, 2008).

Socially, children with disabilities are presented with cultural preferences that keep them from excelling in their communities. For example, in India it is not appropriate to eat with your left hand, not due to right-hand dominance but because of the cultural significance of the right hand being the "clean hand" (Emeneau, 1987). If a student has a physical impairment impeding eating with their right hand, they are often kept out of schools. Society also deems male figures with a medical degree as having a more prominent impact in their culture, putting priority on medical treatments for those with disabilities versus educational needs (Anees, 2014). India is also a culturally diverse society that differs from city to city and village to village. A big part of culture is the language spoken. Within India, there are in excess of 1500 languages, both official and unofficial, spoken across the country (Sengupta & Saha, 2016). Unofficial languages are especially evident in

the rural villages. The language spoken in Mayasandra, for example, is Kannada. This is a language recognized and understood within their small area of the state. Within typical schools in Mayasandra, students are being taught both Kannada and English but not within segregated schools. Within NNCT specifically, students are only taught Kannada, limiting their vocabulary and who they can talk to.

Those with disabilities are not only limited by society but can at times be limited by their families as well. Many families will deny access to services because deprivation is everywhere and if they don't believe the services will increase the child's potential contribution within the household; it is not worth their already limited time and resources (Anees, 2015). Additionally, lack of education creates an attitude of a "one-time fix," such as a pill or medical diagnosis that will clear the symptoms of the disability. The authors of this chapter have witnessed this in their work with families with disabilities. Many families are desperate to have a surgery or prescription to "fix" the problem. Due to some families believing that having a family member with a disability is karma, families may be reluctant to enroll their child in school (Limaye, 2016). Many families of females who have disabilities choose to prepare them for being wives and taking care of their future home and family (Anees, 2014). Women marry into other families, so their immediate family is uninterested in investing in their education while growing up. Therefore, approximately 68 % of school-aged females are not enrolled in school (Kohama, 2012). In Karnataka, the literacy rate of women with disabilities is 7 % compared to 46 % overall for females within the state (Limaye, 2016). In addition, many families are not aware of special schools that are available to meet their children's needs through specially trained personnel. When families seek medical help, medical professionals may recommend sending individuals with disabilities to regular schools. While inclusion is important in schooling, regular school teachers in India are untrained in the teaching methods needed for children with disabilities to reach their fullest potential (Limaye, 2016).

It is estimated that there are 900 schools for the hearing impaired, 400 schools for those with visual impairments, 1000 for students with intellectual disability, and 700 for children with physical disabilities (Bagga, 2007). Since there are millions of individuals with disabilities in India, there are not enough schools with special education services. In addition to the lack of available schools, many schools are not equipped to accommodate individuals with disabilities. According to Kohama (2012), only 18 % of SSA schools are "barrier-free." Barrier-free environments are those in which individuals with disabilities can move around safely, independently, and freely. In schools that are not barrier-free, some children may have difficulties in bathrooms, libraries, classrooms, and playgrounds. It is expensive to add modifications to buildings, so in countries already lacking resources, such as India, making buildings accessible to individuals with disabilities is not viewed as a priority (Kohama).

Within the more rural areas, access to service can prohibit a child with disabilities from receiving special education. The majority of the families in these areas use public transportation to get from rural to urban areas, which can be both costly and time-consuming. For example, Mayasandra is located within a geographically isolated area. Traveling by bus from the rural village of Mayasandra to the urban area of Bangalore can take up to 3 h and cost as much as 150 rupees, one way. This much traveling would also mean time away from work, which most families cannot afford. Aside from that, many children are not able to ride public transportation due to physical impairments, behavior, or other needs related to their disability. These families cannot afford to move to urban areas due to the influx of prices and necessities needed to live there. The resources in urban areas are not accessible nor are they necessarily appropriate for those with disabilities in the rural communities. Not only are urban area services hard to access, services in rural areas aren't always accessible. Unlike Western culture, the majority of families do not own or have access to an automobile. This leaves them walking in order to reach local services, which is oftentimes impossible due to physical impairments, rough terrains, and many

days of unbearable temperatures. NNCT has recognized these problems and provides families with a ride in the school van. It only travels a certain radius and is only accessible for each family twice a week. In addition, there are not special schools located in every village. Some families must travel hours to get to the closest school, making attendance not feasible. This leads to a strain on accessing available services for much of India's population who have been diagnosed with a disability.

Discussion Box 21.2

In rural Karnataka, the median annual household income is 18,900 rupees. Being as transportation to bigger cities can cost up to 300 rupees round-trip, it is nearly impossible for families to access the services desired for those with disabilities. Assuming that a round-trip would cost 300 rupees for an individual to have special education services 5 days a week for 8 months, it would cost a family 48,000 rupees. In addition, if a family were to travel to the larger cities 5 days a week, they would be missing work.

In some villages, like Mayasandra, specialized schools exist, where teachers and therapists from larger cities visit once a month to provide support. There are some issues with this model that do not equate to the services from the larger specialized centers: teachers in these schools do not have the training, the resources are lacking, the time students are in school is limited to 2 days if they ride the bus or 6 days if a family member can bring them (often resulting in that family member staying at the school for the day).

1. If a family member brings a student to school 6 days a week and stays with them, do you think there are ways that family member could be used at the school to enhance service delivery?

2. What are some alternatives to traveling 5 days a week for 8 months to access the services in the larger cities, assuming those services do not exist in the village?
3. What are some suggestions you could make to teachers and/or family members to help increase the access to services for the children who can only come to school 2 days a week?

Strategies to Enhance Services

Although there are many barriers to service delivery in India, especially in the rural areas, there are systems in place to promote access to appropriate services that can serve as models. In Mayasandra, there is already an established international collaboration with the United States. An overall shift in focus to inclusive education could lead to positive outcomes for all students in India. Community-based rehabilitation (CBR) is a model that might lead to better services for all individuals with disabilities in India, including adults.

International Collaboration Another possible way to overcome the barriers to service delivery would be for countries like India to look to established programs for rehabilitation. For example, the United States has a long history of providing special education and rehabilitation services to those with disabilities. While many of the laws in the United States govern those services, the Acts put into place by the government in India can create the path to better services for more people with disabilities in India.

History There has been growing international collaboration within the rural village of Mayasandra. In 2009, a medical brigade from University of Kentucky Shoulder to Shoulder Global (STSG) had an exploratory trip to two villages in southern India, one was Mayasandra. This was coordinated with a retired surgeon from Bangalore who had returned to the village he grew up in. Initial thoughts were that STSG might assist

the community in developing a primary care center similar to the STSG in Ecuador. After a health camp in the village, where around 500 patients were assessed, it was clear to the pediatric team that many children with special health-care needs were not receiving intervention services. The team met with the local community leaders to discuss the special health-care needs of local children. Through strong local leadership and support from STSG, Mayasandra established a nonprofit organization, NNCT, to organize and run a program for children with disabilities. NNCT and STSG organized a community-wide survey to identify the level of special needs in the population. This survey identified 3.5 % of children with special needs, primarily neurodevelopmental. The initial model was to partner with the Spastics Society of Karnataka to train local members of the community for a 6-month-long training. Once trained, they returned to Mayasandra and opened a center, serving children there and in surrounding communities. Children were bused from nearby villages. The Spastics Society sent a team once a month to the center to oversee treatment plans and work with staff they had trained. In 2013, a group of physical therapists accompanied the doctors to assess the physical needs of the children in and around the community. Many families that had children with disabilities traveled to see the doctors and physical therapists; the majority of the children with physical disabilities also had intellectual disability. In 2014, special education faculty from University of Kentucky accompanied the group as an exploratory trip to evaluate the needs of the children attending the clinic. It was determined that the majority of the 100 children seen had developmental and physical disabilities. The 2013 camp in Mayasandra sparked the need for a true interdisciplinary assessment of the students coming to the clinic. Each year the group traveling to Mayasandra has grown to include doctors, therapists, teachers, students, and families.

The services STSG offers to this self-contained school for children and adolescents with disabilities are unique for India in that it is truly interdisciplinary. Teams work collaboratively to assess children in ten domains: environment, academic, cognitive, communication, motor-sensory, social, emotional, adaptive, behavioral, and medical. Most of the time the groups have doctors, therapists, teachers, and students from India and the United States working together with the family. The assessment provides a way to determine what the needs are for the child and the family; suggestions can be made for school, home, and access to the community.

In India, many of the special schools are run by local doctors. The NNCT school in Mayasandra is no different. A local surgeon saw a need and worked with STSG and Spastics Society of Karnataka to create a school for students with various types of disabilities. The surgeon and a group of teachers started a school in a two-room clinic. It has grown to a two-building school with classrooms, a therapy room, a cafeteria, offices, and bathrooms.

The teachers had very little training, and the doctor set the school up in a medical model where many kids came to school and waited to be called in for their turn in school. In 2015, the special educators and physical therapists began including professional development training for the teachers and staff in the school. They modeled easy strategies and provided a list of baseline activities for each child they assessed. The thought was if the teachers knew where to start and how to teach, they would be better suited to meet the needs of the diverse population they served. It became clear that this was not enough. In the Spring of 2016, the University of Kentucky, with the help of Rotary Club of India, sent a teacher to live in Mayasandra for 4 months. During this time, the teacher worked alongside the staff and administration in order to better train and equip them to provide services to students. She also was able to educate staff and families on disabilities and answer questions regarding their children that they had never been able to ask. Although language and cultural differences proved to be two major barriers when working alongside NNCT, she was also able to teach and learn throughout the experience. A lot of what she did involved working one-on-one with staff to model teaching strategies, including systematic instruction. The majority of the staff believed behaviors could not be fixed and many children could not be taught, so she also worked

alongside them to show that behaviors can be both learned and unlearned, giving them strategies to change behaviors and increase learning. She worked together with administration, demonstrating different ways to monitor student progress in order to track student learning. This progress monitoring was designed to inform instructional decisions, be shared with family, and demonstrate the school's work when requesting funding from different organizations. Ultimately, the teacher worked with them, giving them a toolbox of sustainable strategies that they could use, making the school more independent and less dependent on large organizations and Western professionals.

Case Study

Naveen is a student who has been attending NNCT for 3 years. He receives both physical therapy and special education. He is currently 8 years old and lives with his mom, dad, brother, and grandma in a neighboring village close to Mayasandra. His family is native to the village, and his dad and grandmother operate a storefront that is connected to their house. His mother cuts hair for a living. Naveen travels by bus twice a week and is dropped off by his mother the other 4 days. When first starting NNCT, Naveen was not able to sit up on his own, move from sitting to standing without assistance, balance without assistance, or use the bathroom independently. These physical limitations made it impossible to attend school with his typical peers. While at school, Naveen receives physical therapy services that help to strengthen muscles needed for gross motor skills (e.g., sitting, walking) by a physical therapist. After lunch, Naveen receives 1–2 h of special education. For 3 years, Naveen received physical therapy daily, and his family was taught how to practice with him at home. The teachers integrated physical therapy into his classes, and he slowly began to build the muscles needed to become more

independent. Naveen is now able to sit and stand on his own, as well as walk with assistance. Although he is still unable to use the bathroom or walk independently, he will be enrolling in a general education school starting next school year because of the advances made while attending NNCT.

Questions:

1. What role might the integration of Naveen's physical therapy into his classes have on his progress?
2. What role might training Naveen's family in his physical therapy exercises have on his progress?
3. If Naveen's family had waited until he was 10 to bring him to NNCT to begin receiving physical therapy and special education, do you think he would still be transitioning to the general education school?
4. What could the teachers and therapists at NNCT do to facilitate more inclusive placements for their students in the general education schools?

Future Although the school in Mayasandra has come a long way, there is still much that needs to be done. Training teachers at these smaller specialized schools in realistic and sustainable practices is critical. Considering a shift toward inclusive education would be a next logical step in teacher training. Looking into a model like CBR would be a meaningful way to ensure services for those with disabilities expand into adulthood.

Sustainable Training Practices Teachers working at NNCT need to be trained in the assessment protocol so that children need not wait until the annual STSG trip for an initial assessment. They are currently a part of the assessment process, so teaching them how to identify the critical needs of the children would be invaluable. Teachers need additional instruction in creating and maintaining a schedule, classroom procedures, small and large group teaching, and age appropriate instruction.

This process was started when the teacher from the United States lived with them for 4 months. This program is still, however, run by a doctor. It is critical that the schedule resembles more of a school day and less of a doctor's office. They need to learn evidence-based practices when delivering behavioral and academic instruction to students, so bigger gains can be made. The training for these teachers has been so limited. They rely on monthly visits to know what skills to target and, if there is time, how to begin to teach them. It would be empowering if the teachers were taught a few high-impact instructional strategies that they could use with a variety of skills. For example, they could be taught to use system of least prompts to teach chained tasks and constant time delay to teach discrete tasks. Behaviorally, the teachers need to learn how behavior principles influence behavior change. The data collected for academic tasks and behaviors need to be monitored to ensure it is being collected with fidelity and being used to make instructional decisions. This is a program that was also started when the teacher from the United States was visiting; however, a system needs to be in place to ensure this practice is continued. Although there will continue to be new needs identified, regardless of what is implemented, the STSG team needs to ensure that all recommendations are realistic and sustainable given all of the factors described in this chapter.

Shift to Inclusive Education The Ministry of Human Resource Development is responsible for training regular education teachers, whereas the Rehabilitation Council of India is responsible for training special education teachers (Kohoma, 2012). This makes the shift toward inclusion more difficult due to the separation of training, gap in curriculum, and the lack of collaboration of training between regular and special education teachers. Educators throughout India are not trained to design and implement special education practices (Sharma & Deppeler, 2005). In order to promote inclusion in both regular education and separate schools across India, an inclusive curriculum and inclusion training needs to be included to teaching practices (Limaye, 2016; Parua & Kusum, 2010).

All students in India have been given a right to education with the National Policy on Education passed in 1986 (Singal, 2006). There are differing philosophies about where children with disabilities should be educated. Some argue for special schools, where students can excel in a school that is designed to meet their needs; other argue for integrated education, where at least some children with disabilities should be educated with their typical peers. Inclusive education has been a topic of conversation for almost 20 years. In India, inclusion is not for all children. "A child with disabilities must fulfil a range of prerequisites before being included into the mainstream" (Singal, 2006, p. 360). The prerequisites include things such as ability to interact with peers, quick acquisition of new skills, and ability to attend to tasks.

Current barriers exist, making inclusive education for all nearly impossible. One issue is that assistive devices are often not accepted by society (Singal, 2006). For a student to be included appropriately, it is likely assistive devices will be needed. Another issue is that some schools are structured around a strict curriculum (e.g., National Institute of Open Schooling) (Singal, 2006). For some students with disabilities, an alternative curriculum might be necessary.

Regardless of barriers to inclusive education, the fact that it is the topic of conversation is promising. Students with disabilities are being included when they meet the prerequisites. As more children with disabilities are being educated in general education schools, there is a possibility that teachers will become more confident, and institutes of higher education will begin intentionally training teachers in appropriate methods. These factors are what led the United States to more meaningful inclusion; if India stays on a similar trajectory, true inclusive education could become a reality in the future (Singal, 2006).

Community-Based Rehabilitation CBR is designed to ensure people with disabilities reach their fullest potential (Crishna, 1998). To do this, CBR works to ensure accessibility to all of the things a person would need access to

Research Box 21.1

See Parua and Kusum, 2010.

Objective: The objective of this study was to determine what teachers believe about children's ability to learn and problem behaviors while in inclusive settings. The authors looked at the differences between urban and rural settings and men versus women.

Method: Authors developed a 23-question survey. It was given to 300 teachers, 150 in urban settings and 150 in rural settings, equally split between female and male teachers, in Himachal Pradesh, India. All teachers worked in inclusive schools. For comparison of urban to rural and males to females, mean, standard deviation, and t-Ratio scores were used to determine differences in views on ability to learn and problems for children with disabilities in inclusive settings.

Results: Teachers in both urban and rural settings had similar beliefs about children with disabilities and their ability to learn and problems encountered in inclusive settings. Female teachers were more likely to have positive attitudes toward learning ability for all students within inclusive settings than male teachers.

Conclusions: There was no difference in views between urban and rural settings on the belief that inclusive education could be beneficial for the learning and behavior for children with disabilities. There was a difference between female and male views, with the females having more positive attitudes toward inclusive education outcomes for individuals with disabilities. Overall, the results support the inclusive teaching framework.

Questions:

1. How do the results of this study mirror the cultural issues faced by those living in India?

2. Since this study shows that inclusion is viewed to have a positive impact on the learning and behavior of students with disabilities, what impact could this have on the future of special education and rehabilitation in the future?

3. What are some possible factors that could be attributed to the similar results between urban and rural schools? What are some possible factors that could be attributed to the differences in results between male and female teachers?

(e.g., community, services, social activities). The accessibility should be designed in authentic settings, those used by people without disabilities. To design programs for a person to achieve independence and social acceptance in India, the factors described earlier in the chapter (e.g., family, spirituality) must be taken into consideration. India's culture is well suited for the CBR approach since family unity and community cohesiveness are common (Janardhana et al., 2015).

Summary

Traditions, values, beliefs, and education have been discussed through this chapter and the impact that each have on individuals with disabilities as well as their families. Family and spirituality are two of the main foundations that individuals in India live by. Families stick together throughout generations, and spirituality plays a major role in the acceptance of individuals with disabilities. Throughout this chapter the obstacles of individuals with disabilities in India have been discussed. Lack of transportation, teacher training, and religious views, among many others, have been barriers for individuals with disabilities receiving educational services. The expenses to receive such services, as well as the location of services available, cause barriers to families seeking help, especially in rural India. Emphasis has been placed on the educational

advances that are needed in order to increase the number of individuals with disabilities receiving education as well as an improved value of education that they are receiving. Teacher training, inclusive education, and CBR are a vital part in the educational system in other countries. Therefore, these recommended practices could produce a solid foundation toward an educational system to enhance the education of individuals with disabilities in rural India.

Resources

Factors Influencing the Accessibility of Education for Children with Disabilities in India: http://ger.mercy.edu/index.php/ger/article/viewFile/236/217

Government of India: Ministry of Statistics and Programme Implementation: http://mospi.nic.in/.

Inclusive Education in India: A Country in Transition: http://intldept.uoregon.edu/wp-content/uploads/2012/12/INTL-UG-Thesis-Kohama.pdf

Inclusive Education in India: Past, Present, and Future: http://onlinelibrary.wiley.com/doi/10.1111/1467-9604.12079/pdf

Persons with Disability & the India Labour Market: Challenges and Opportunities: http://www.ilo.org/wcmsp5/groups/public/---asia/---ro-bangkok/---sro-new_delhi/documents/publication/wcms_229259.pdf

Learning Exercises
Self-Check Questions

1. What is the division between India's urban and rural areas and the resources that are available or lacking in both?
2. How does the caste system impact views on disability? What impact does this have on the services provided to those with disabilities?
3. How do the beliefs in karma and dharma impact views on disability? What impact does this have on the services provided to those with disabilities?

4. What is the importance of teacher training in the application of special education services? How is this different in urban and rural settings across India?
5. Given the international collaboration between STSG and NNCT, what are some considerations the team from the United States must make when making recommendations for services and program planning?

Experiential Assignments

1. As stated in the text, accessibility of school buildings is an issue in educating individuals with disabilities. Reflect on the buildings you go through daily that support accessibility for individuals with disabilities. Critique the importance of building structures such as ramps, elevators, wide restrooms, etc. Imagine these buildings without such structures and the barriers this would produce for individuals with physical disabilities.
2. Compare and contrast the history of the laws in disability in the United States to those in India. Design a plan for India's government that would be the logical "next step" for disability in regard to education, inclusion, and rehabilitation services.
3. Mayasandra is a large farming village. Outline a list of jobs and skills that could be done as a result of this type of work (e.g., planting crops, selling crops in the village). Create a plan for teaching individuals with disabilities to learn the skills at school and in the community while still in school, as well as a transition plan for employment once they age out of school.

Multiple-Choice Questions

1. Where do the majority of those with disabilities in India live?
   (a) Urban areas
   (b) Suburban areas
   (c) Rural areas
   (d) Both urban and rural areas

2. Where are the majority of the quality services for people with disabilities found?
   (a) Urban areas
   (b) Suburban areas
   (c) Rural areas
   (d) Both urban and rural areas
3. Who organizes and runs most of the special schools in India?
   (a) Teachers
   (b) Doctors
   (c) Nurses
   (d) Therapists
4. Which of the following is/are the main reasons it is hard for individuals with disabilities to receive services in India?
   (a) Limited access to transportation
   (b) Distance to services
   (c) Rough terrains and unbearable temperatures
   (d) All of the above
   (e) None of the above
5. India's culture and subsequently views on disability are shaped by which of the following?
   (a) Social class
   (b) Family
   (c) Spirituality
   (d) All of the above
   (e) None of the above
6. Which of the following has historically had the biggest influence on a person's life in India?
   (a) Government
   (b) Spirituality
   (c) Family
   (d) Social class
7. Who supports teachers in the special education schools in rural villages in India?
   (a) Government
   (b) Families
   (c) Local general education schools
   (d) Special education schools/centers in urban areas
8. Why is communication between regions in India sometimes difficult?
   (a) There are many different languages spoken in India
   (b) People living in one region do not get along with people living in other regions
   (c) Young people only speak English

   (d) All of the above
   (e) None of the above
9. Which of the following would likely be a job for an adult with a disability in Mayasandra?
   (a) Banking
   (b) Farming
   (c) Medicine
   (d) Teaching
10. What is a likely outcome for the international collaboration between NNCT and STSG?
    (a) Medical cure for disability
    (b) Inclusion in general education schools
    (c) Appropriate program planning in multiple domains
    (d) All of the above
    (e) None of the above

Key

1 – C
2 – A
3 – B
4 – D
5 – D
6 – C
7 – D
8 – A
9 – B
10 – C

References

Allchin, B., & Allchin, F. R. (1993). *The birth of Indian civilization: India and Pakistan before 500 B.C.* Gurgaon, Haryana: Penguin Books India.

Anees, S. (2014). Disability in India: The role of gender, family, and religion. *Journal of Applied Rehabilitation Counseling, 45*(2), 32–38.

Bagga, K. S. (2007). *Ensuring disabled people their right to education*. Retrieved from http://www.indialawjournal.org/archives/volume1/issue_4/article_by_bagga.html

Beautiful Gate Special School Admissions. (n.d.). Retrieved from http://www.bgssindia.org/ admissions/

Byker, E. J., & Austin, S. F. (2014). Bangalore's challenge: The social construction of educational technology in India's Silicon Valley. *The Global Studies Journal, 6*, 25–31.

Census Population. (2015). *Mayasandra population – Tumkur, Karnataka*. Retrieved from http://www.census2011.co.in/data/village/612386-mayasandra-karnataka.html

Chavan, B. S., & Rozatkar, A. R. (2014). Intellectual dis-
ability in India: Charity to right based. *Indian Journal
of Psychiatry, 56*, 113–116.

Chekki, D. A. (1996). Family values and family change.
Journal of Comparative Family Studies, 27, 409–413.

Crishna, B. (1998). What is community-based rehabilita-
tion? A view from experience. *Child: Care, Health,
and Development, 25*, 27–35.

Datt, G., & Ravallion, M. (2002). Is India's economic
growth leaving the poor behind? *The Journal of
Economic Perspectives, 16*(3), 89–108.

Doniger, W., Smith, B. K., van Buitenen, J. A. B., Basham,
A. L., Narayanan, V., & Dimock, E. C. (2016).
Hinduism. In *Encyclopedia Britannica*. Retrieved
from https://www.britannica.com/topic/Hinduism

Emeneau, M. B. (1987). The right hand is the 'eating hand':
An Indian areal linguistic inquiry. *Dimensions of Social
Life: Essays in Honor of David G. Mandelbaum*, *48*, 263.

Henderson, C. E. (2002). *Culture and customs of India*.
Westport, Conn: Greenwood Publishing Group.

Hernandez, V. T. (2008). Making good on the promise
of international law: The convention of the rights of
persons with disabilities and inclusive education in
China and India. *Pacific Rim Law and Policy Journal
Association, 17*, 497.

Hui, C. H., & Triandis, H. C. (1986). Individualism-
collectivism: A study of cross-cultural researchers.
Cross-cultural Psychology, 17, 225–248.

India Register General and Census Commissioner.
(2011). *Population enumeration data (final popula-
tion)*. Retrieved from http://www.censusindia.gov.
in/2011census/ population_ enumeration.html

Jacobson, D. (2007). Hinduism and Buddhism. *Faces,
24*(2), 35.

Janardhana, N., Muralidhar, D., Naidu, D. M., &
Raghevendra, G. (2015). Discrimination against dif-
ferently abled children among rural communities in
India: Need for action. *Journal of Natural Science,
Biology, and Medicine, 6*, 7–11.

Kohoma, A. (2012). *Inclusive education in India: A
country in transition*. Retrieved from http://intldept.
uoregon.edu/wp-content/uploads/2012/12/INTL-UG-
Thesis-Kohama.pdf

Limaye, S (2016). *Factors influencing the accessibility
of education for children with disabilities in India*.
Retrieved from http://ger.mercy.edu/index.php/ger/
article/viewFile/ 236/217

Llewelyn, J. E. (2015). Caste: Religion and society in
India. *Religion Compass, 9*(3), 77–85.

Lorenzen, D. N. (2016). Who invented Hinduism?
Comparative Studies in Society and History, 41,
630–659.

Mines, M. (1988). Conceptualizing the person:
Hierarchical society and individual autonomy in India.
American Anthropologist, 90, 568–579.

Ministry of Statistics and Program Implementation. (2011).
Disability in India: A statistical profile. Retrieved

from http://mospi.nic.in/publication/disability-india-
statistical-profile-2011-1

Mullatti, L. (1995). Families in India: Beliefs and realities.
Journal of Comparative Family Studies, 26, 11–25.

Niranjan, S., Nair, S., & Roy, T. K. (2005). A socio-
demographic analysis of the size and structure of
the family in India. *Journal of Comparative Family
Studies, 36*, 623–651.

Parua, R. K., & Kusum. (2010). A study of teachers view/
perceptions with regard to learning capacity and prob-
lems of students with special needs in inclusive educa-
tion setting. *International Journal of Education and
Allied Sciences, 2*, 119–124.

Planning and Statistics Department, Government
of Karnataka. (2006). *Karnataka: Human
Development Report 2005*. Retrieved from: http://
planningcommission.nic.in/plans/ stateplan/ sdr_
pdf/shdr_kar05.pdf

Ram, U., Strohschein, L., & Gaur, K. (2014). Gender social-
ization: Differences between male and female youth in
India and associations with mental health. *International
Journal of Population Research, 2014*, 1–11.

Schimmel, A., Rahman, F., & Mahdi, M. S. (2016). Islam.
In *Encyclopedia Britannica*. Retrieved from https://
www.britannica.com/topic/Islam

Sengupta, D., & Saha, G. (2016). Identification of the
major language families of India and evaluation of
their mutual influence. *Current Science (00113891),
110*(4), 667–681. doi:10.18520/cs/v110/i4/667-681.

Sharma, U., & Das, A. (2015). Inclusive education in
India: Past, present and future. *Support for Learning,
30*(1), 55–68.

Sharma, U., & Deppeler, J. (2005). Integrated education
in India: Challenges and prospects. *Disability Studies
Quarterly, 25*(1).

Singal, N. (2006). Inclusive education in India:
International concept, national interpretation.
*International Journal of Disability, Development and
Education, 53*, 351–369.

Singh, D. K. (2000, April). *Physical disabilities in the
land of karma theory*. Paper presented at the Council
for Exceptional Children Special Education World
Congress, Vancouver, Canada.

Spastics Society of Karnataka. (n.d.). Retrieved from
http://www.spasticssocietyofkarnataka.org/

Srinath, S., Girimaji, S. C., Gururaj, G., Seshadri,
S., Subbakrishna, D. K., Bhola, P., & Kumar, N.
(2005). Epidemiological study of child and adoles-
cent psychiatric disorders in urban and rural areas
of Bangalore, India. *Indian Journal of Medical
Research, 122*, 67–79.

Tiwari, S. C., & Pandey, N. M. (2013). The Indian con-
cepts and mental health in old age. *Indian Journal of
Psychiatry, 55*, S288–S292.

Williams, R. V. (2013). The more things change: Debating
gender and religion in India's Hindu laws, 1920–2006.
Gender and History, 26, 711–724.