Segregation Hurts

Voices of Youth with Disabilities and Their Families in India

Pavan John Antony

Adelphi University, New York, USA

Segregation Hurts is a book that explores the stories of six families who have children with disabilities. The families who reside in the south west of India shared their daily experiences living with a child with a disability. Irrespective of the diverse socio-economic statuses and religious beliefs, families shared common challenges raising a child with a disability in the Indian society. These children faced exclusion and denial of admission to local public schools due to their disability and they were forced to seek admission to a special school in their neighbouring community. Public schools in India continue to deny admission to millions of children due to their disabilities and are an invisible minority in the society. This book provides a novel and unique perspective about the nuances and daily struggles of families who are silenced and shut out due to the shortcomings and oppressive nature of the education system. Further an indepth analysis and critique is made of the treatment and education of children with disabilities in India. Dr. Antony is a strong advocate of inclusive schooling and this book will share his expertise within international contexts.

“I highly recommend Dr. Antony’s book. It gives a new insight into the life and lessons of Gandhi.”
- Arun Gandhi, President, Gandhi Worldwide Education Institute, Rochester, NY, USA.

Pavan Antony has written a compelling overview of the education of children with disabilities in India through six stories. There are commonalities in the families’s experiences, even though they come from different backgrounds. The candid conversations the researcher had with the families brings their hopes, fears and dreams to life. The move to inclusive practices in a developing country is difficult and Pavan Antony captures the macro and micro challenges through this powerful narrative.
- Dr. Vianne Timmons, President and Vice-Chancellor, University of Regina, Canada.

Pavan Antony has given us deeper insight into the lives of families that include people with disabilities in India. Through the stories of six individuals, their parents and siblings, the variables of class, religious tradition, cultural identity and human resilience are explored. Pavan’s book provides an enriching cultural lens with which to explore disability, humanity and the dignity of each person.
- Barbara Trader, Executive Director of TASH, Washington, USA.
Segregation Hurts
STUDIES IN INCLUSIVE EDUCATION
Volume 19

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Scope
This series addresses the many different forms of exclusion that occur in schooling across a range of international contexts and considers strategies for increasing the inclusion and success of all students. In many school jurisdictions the most reliable predictors of educational failure include poverty, Aboriginality and disability. Traditionally schools have not been pressed to deal with exclusion and failure. Failing students were blamed for their lack of attainment and were either placed in segregated educational settings or encouraged to leave and enter the unskilled labour market. The crisis in the labor market and the call by parents for the inclusion of their children in their neighborhood school has made visible the failure of schools to include all children.

Drawing from a range of researchers and educators from around the world, Studies in Inclusive Education will demonstrate the ways in which schools contribute to the failure of different student identities on the basis of gender, race, language, sexuality, disability, socio-economic status and geographic isolation. This series differs from existing work in inclusive education by expanding the focus from a narrow consideration of what has been traditionally referred to as special educational needs to understand school failure and exclusion in all its forms. Moreover, the series will consider exclusion and inclusion across all sectors of education: early years, elementary and secondary schooling, and higher education.
Segregation Hurts

 Voices of Youth with Disabilities and Their Families in India

Pavan John Antony

Adelphi University, New York, USA
DEDICATION

This book is dedicated to my mother and father who are the people behind my growth, and to all the families and children of people with disabilities in India.
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I begin with my parents especially my mother, Sophiamma who always told me “...you can contribute to change and you will do it using the tool of education...” She inspired me from childhood, a lady who spent sleepless nights worrying about my future. If she had not taken time to get up and wake me up at 4:30 a.m. every day during my school years, I would not have been in this position. My father, CA Antony, who I think has sacrificed his entire life for educating his children, always supported my mother’s decision. He never let me know that financing education is hard. He was always quiet, but his silence was an indirect support, gave me the courage to prove to him that his son is capable and his effort to educate me from childhood was worth it. Regular phone calls from my sister (Deepom), brother in law (Benny) and chats with my three year old niece (Michelle) provided me the opportunity to overcome homesickness. My wife Jenny has been a huge help during the typing process of this book. My daughter, Hannah, has been very cooperative and often sat next to me playing with her toys while letting me work.

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Lastly I thank Dr. and Mrs. Roy who have played an important role during my data collection and work with families of children with disabilities in India. A special thanks to all the families and their children with disabilities who participated voluntarily for this study. I dedicate this book to all the children with disabilities in India.
This book discusses the social, cultural and educational attitudes towards disability in the state of Kerala, India. The book highlights the real life stories of six families, parents of children with disabilities, living in different socioeconomic status and possessing different educational qualifications. Qualitative data collected through in-depth interviews and observations were used for developing this book. In a society where people are classified according to their socioeconomic status, this book reveals some important factors that need to be considered by professionals, policy makers and the public, while working with families and children with disabilities. Findings reveal that families and children with disabilities belonging to upper, middle and lower class, educated, less educated and uneducated families face common challenges. All the parents and their children with disabilities shared that they were not only unaware of their legal rights related to disability or inclusive education but were also unaware about the actual diagnosis of their children and the impact of it on their future. All the parents have the common belief that their children will be dependent upon their parents or siblings for their entire life. The parents inform us that lack of opportunities for people with disabilities in any community is due to the lack of awareness among public about different types of disabilities.

Today, special schools continue to be the only major setting that offers education or training for most children with disabilities. The parents of children with disabilities who contributed to this book share their children’s incompetency to enter real world after several years of schooling in segregated settings. The real life stories of parents and their children with disabilities included in this book will inform us about the importance of including all children in public schools around the globe.

Implementing inclusive education is the only way to create awareness, bring in change and thus build an inclusive community.
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“Many of the things we need can wait. But the child cannot. Right now is the time his bones are being formed, his blood is being made and his sense being developed. To him, we cannot answer, ‘Tomorrow’. His name is ‘Today’” (Iyer cited in Siddiqui, 2007, p.163).

The education and equal opportunities for children with disabilities is an ongoing issue around the globe. The specific issues vary from one country to another. When school officials cannot deny admission to children based on a disability in countries like the United States, millions of similar children in places like India struggle to find an education or disability related services in their Indian home lands. According to Alur (2001), “The institution of the family and its value system emerges as the strongest agency of care” (p.290). The majority of services for people with disabilities in India are carried out by parents or family members.

India, the second largest populated country in the world, has traditions and cultures that are more than ten thousand years old. In 29 states, populations speak unique languages and practice distinct cultures. The country has 18 official languages with over 1500 dialects (Timmons & Alur 2004). There are Hindus, Christians, Muslims, Sikhs, Parsis, Jains and devotees of a few other religions, residing in the same country. Because of these differences in languages, religions, culture, traditions and practices, each state in India is culturally distinct. Irrespective of all these diversities, family practices in the country have many commonalities. Throughout India, family is considered primarily responsible for its members.

Usually when a child is born into any family, s/he is welcomed with much joy, happiness and excitement. In India the birth of a newborn is the occasion for a big celebration accompanied by various traditional cultural practices and rituals by families and friends. Many people make offerings to their Gods for blessing their family with a newborn. In some religions, a newborn is regarded as the flame of their family and is expected to carry on the family name and traditions. According to Mullatti (1995), “A child is believed to be a fruit given by god” (p. 9). Srinivasan & Karlan (1997) considered children to be ‘innocent beings’ in the society. Therefore a child born in an Indian society receives much attention, care, and celebrity from the members of family, community, and from their respective religious groups. The feeding of a newborn, naming of a child, onset of student life, and getting a first job are some of the important events families celebrate with their son/daughter. Often they perform many rituals in accordance with the family’s culture and background as these milestones occur.
The reception of a newborn child becomes quite different if the newborn child has some disabilities. In many cases, the child is greeted with disappointment, helplessness and frustration by their family and community. Further, the child with special needs and h/her family is usually left with limited choices to learn about the developmental delays, or to identify resources to educate the child. Thus most families are forced to care for their son or daughter with disability within their home setting with limited or no resources. Many communities lack an appropriate support system to help families cope with the birth of a child with special needs. “The Karmic theory of traditional Hindus about the present being a reflection of past deeds is strongly entrenched” (Timmons & Alur, 2004, p.42). People strongly believe that the birth of a child with a disability is the result of a family’s past deeds. However, all the participants in this book except one father in the upper class did not believe that past karma of ancestors resulted in the birth of their child with disability. In many cases, the segregation of a child with disabilities and his or her family by the people and the community at large begins from the time of birth. In some families, the birth of a child with special needs is considered a personal tragedy or an individual responsibility (Timmons & Alur 2004). The major reason for these strong beliefs is likely due to the lack of counseling and education on disabilities for parents and people in the community at large. The families rely heavily on the medical model and seek the advice of medical doctors for treatment and daily planning, with a great hope that their child’s disability will be cured one day. The medical model dominating the field of disability has already been critiqued (Oliver 1978, 1996). According to this model, disability is located within the individual and efforts are made by medical professionals to fix the individual so that h/she fits into h/her surrounding environment. Parents of children with disabilities in India at large continue to seek help from medical doctors and other professionals for a cure in their child’s disability while it is not curable. It could be also argued that in places like India, parents do not have many other options other than consulting with medical doctors for professional advice. So the power to dominate comes in naturally into the hands of medical doctors. As a result they make decisions for people with disabilities, “… where they should live… work… what kind of school they should go to, what kinds of benefits and services they should receive and in the case of unborn disabled children, whether they should live or not” (Oliver, 1996, p.36).

It is very common for neighbors in the community to approach families of children with disabilities with advice on who can cure their child through certain medicines, prayers by religious leaders or faith healing. There are also religious people who are ready to get rid of evil spirits in children for good sum of money. In other words, on top of the medical model, lives of people with disabilities and their families are also ruled by religious model. The cultural and religious beliefs ruling the minds of average Indians is well recorded in the literature (Alur, 2001; 2003; Kalyanpur, 2008; Mullatti, 1995; Timmons & Alur, 2004). There are parents of children with disabilities who strongly believe that disability in children can be cured through religious rituals or ceremonies. Existing literature from India reveals
INTRODUCTION

that disability in children is seen as the result of karma or past deeds (Alur, 2001; 2003; 2007, Mullathi, 1995; Timmons & Alur, 2004). However, the chapters included in this book contradict this literature. The parents inform us that similar beliefs exist among the general public and not among parents of children with disabilities. These findings support that personal tragedy theory of disability is also prevalent in India. According to personal tragedy theory, disability is “…some terrible chance event which occurs at random to unfortunate individuals” (Oliver, 1996, p.32). In India, people with disabilities and their families are looked upon with sympathy and pity by a majority of people. The strong cultural traditions and religious beliefs entrenched in the people reflect negatively on many citizens who have a disability in India. In many places across India, helping people with disabilities with money or other personal possessions is considered as helping one’s own faith or helping oneself. People begging on streets or in front of religious places are very common scenes in India. Helping beggars especially in front of religious places is considered a repentance for one’s past actions. These kinds of practices further disable individuals with disabilities and force them to remain isolated and excluded from the mainstream society.

Education and the Kerala State

In India, children with disabilities usually receive their education and other services in special schools and other settings strictly segregated from the public school system. The country also has a strong history of segregating people based on caste. As mentioned earlier, people who were born to a poor socio economic class were classified as scheduled caste or scheduled tribes. Today these minority groups are also called Dalits. According to Webster (2001), people in India gave themselves the name Dalit or oppressed for belonging to the bottom of the society in Indian hierarchy. They were known as Untouchables, because their presence itself was considered to be so polluting that contact with them was to be avoided at all costs. People who are classified as scheduled caste were earlier known as untouchables. In other words, people who belong to other classes refused to touch or be in physical contact with these individuals. There are great gender differences and inequalities between a boy and girl child in the country. India also has one of the lowest female literacy rates in the whole of Asia. Disability cut across caste evenly and these individuals remain invisible from the mainstream society during their entire life. Historically, Brahmins who are a higher class minority in Hindu religion, “…tended to disinherit those who suffered some form of disability” (Buckingham, 2011, p. 421). Buckingham says that any religious rituals performed by people with disabilities for the well-being of his family was considered to be of low ritual value. So a son who had the right to perform funeral rituals for his father, for example was not able to perform that ritual due to his disability (Buckingham, 2011). Men with a disability were not allowed to enter a temple nor be near an altar are also recorded (Dorman as cited in Buckingham, 2011). So there is evidence that a child with disability whether born
into a rich or poor family faced similar discrimination. In other words it can be
argued that individuals with disabilities are treated similar to the untouchables in
the nation. Today, while other states within India still battle with the caste system,
Thomas & Thomas, 2002), in Kerala any sort of caste discrimination is considered
‘a tale of the past’ (Ramanathaiyer & Macpherson 2000, p.3).

Kerala is a state in the Southern part of India with a total population of 29 million
people accommodated in an area of 38,863 sq.km. This is the only state in India
formally recognized as ‘totally literate’ and claims a population with the highest
literacy rate in India (Chandran 1994; Ramanathaiyer & Macpherson 2000). The
achievements in the social sector made by Kerala state are well documented in the
literature (Dreze & Sen 1996; Mukundan & Bray 2004; Parayil, 2000; Prakash
1994; Ramanathaiyer & Macpherson 2000). A boy or girl child born in the state
of Kerala enjoys similar privileges while this is not true in several other states in
India. They receive the same treatment at home, school and in the community. This
happens while female infanticide is still prevalent in many states in India. As female
infanticides no longer happens in Kerala, Ramanathaiyer & Macpherson (2000)
consider girls as lucky to be born into this state in South west India. Girls in kerala
receive an equal education like the boys and enjoy common privileges in college
and at work settings. Today when many states struggle to end child marriages, child
labor and homelessness, kerala state considers these as issues of the past. Kerala state
has also made remarkable progress in rural development. Safe drinking water is
readily available for people in urban and rural areas. Free medical services through
government hospitals and free education through public schools in remote places are
very common in Kerala. Today government has also succeeded in building roads
in the remote places, thus connecting villages to towns. So people in the state have
more privileges than ever before. However, the education of children with disabilites
in the Kerala state takes place in segregated special schools as in any other state.
Similarly, most of the special schools or organizations operate mainly in urban
areas, while seventy percent of Indians live in rural areas (Timmons & Alur, 2004).
Further, as these schools mostly charge fees, they become inaccessible to the poor.
So it is very clear that education of a poor child with a disability in existing special
schools is nearly impossible; children, whether rich or poor in rural areas, have no
access to any education.

Status of People in the Society

In the Indian culture, there are wide gaps between rich and poor people. According
to Nambissan (2010) more than 300 million people, 39.26% of the Indian population
was in extreme poverty during the year 2008. According to her this number is below
the international poverty line of $1.25 a day. Further, the poverty in rural areas are
different from the urban area. As of 2008, only 30% of people in rural areas live
in permanent housing compared to 73% in urban areas, less than 10% have toilet
facilities in rural areas compared to 64% in urban area, 72% have access to safe or portable drinking water in rural areas compared to 93% in urban areas and over 50% of villages are yet to be connected by roads Kalyanpur (2008). It is important to note that Indian government has undertaken new initiatives to improve the quality of lives of people in all over India So the above mentioned number could vary significantly from one year to the next. There are people in India who are classified as scheduled caste, scheduled tribes, upper class, middle class, lower class and as people below the poverty line. Individuals who were discriminated as ‘ex-untouchables’ in caste system are called Scheduled Castes and those ‘…who have experienced neglect and cultural marginalization…’ are called Scheduled tribes (Nambissan, 2010, p.730).

The Government of India has also classified people based on their income into upper, middle and lower class. These gaps between people based on socioeconomic status can be observed in places like schools and work places. Kalyanpur & Gowramma (2007) have highlighted the strong influence of the caste system in Indian society, relegating menial jobs (for example: carpentry and shoe making) to a lower caste and positions of high standing (eg: doctor, engineer, bank officer) to higher caste.

Similarly in the education system, public schools are considered to exist for the poor and private schools for the rich. Public schools are mainly run by the states and students receive instruction in the states regional language free of cost. The private schools offer instruction in English language and charge fees for their services. This makes private schools accessible only to the middle and upper class families in the society. As English is a globally accepted language and has the power to help you earn an elite status and improve one’s own life, private English medium schools has gained wider acceptance among the middle class and rich people. The increase in the number of people in the middle class abandoning state over the last two decades has already been recorded (Nambissan, 2010). In other words children born to rich parents have the privilege of attending private schools, learn foreign languages and access more opportunities to succeed with the help of professionals. While this happens, children attending public schools continue to struggle and find their own ways to succeed with less outside help. These practices of treating people differently are considered an accepted norm by a majority of the citizens. In other words, equality has a different meaning in the Indian culture. As caste system was rationalized by Hinduism, social inequality is accepted as a value of Indian society (Kalyanpur, 2008). This culturally accepted practice of treating people differently has gained acceptance throughout the states.

This ancient and historically rich country has valued the education of its citizens since the 19th century. The initiatives to educate children in India, a ‘non literary society’ during the 19th century, through ‘no separate classes, no marks, no exams’ are documented in the literature (Miles, 1997, p.98). The education of children with disabilities in India during the pre- and post-independence period are also recorded (Alur, 2003). According to the Indian constitution, each state endeavors to provide free and compulsory education for all children until they reach 15 years of age. The law mandates the education for children with disabilities to be accessible in
an appropriate environment till the age of 18 (cited in Pandey, 2004). Irrespective of these laws to educate all children, India has the highest number of out of school children and is one of the country that is most likely to not achieve Education for all by 2015 (UNESCO, 2005). According to a survey conducted in 2000, approximately 27 million (6 to 11 years old) primary school children do not attend school any school in India (Singhal, 2006). Literature reveals that elementary school enrolment rate increased to 95% in 2009 but the drop out was reported to be 49% (Prabhu cited in Nambissan, 2010). There is also evidence those students who are poor and who belong to the minority groups like scheduled caste and scheduled tribes are the early school leavers (Majumdar 2009). Children at a younger age taking up job responsibilities to contribute to house hold income is a common practice that can be observed in most parts of India. So according to the current educational structure in India, students attending private schools have higher chances to succeed compared to those attending public schools. Further education of children with disabilities continues to take place mainly in segregated settings and their lives are worse than the minority groups or poor who remain at the bottom of the society. General educators in public schools at large lack in-depth knowledge and lack training to help children with disabilities. In other words, the current education system promotes education of poor in public school, rich in private schools and force individuals with disabilities to remain home. So the current Indian education system has built in barriers to include all children into the schools. There is a lack of research that provides explanation for the status of inclusive education or equal opportunities for people with disabilities in India. According to Singhal, who reviewed the Indian literature on inclusive education, “…literature in this area is not only scant, but also not easily available” (Singhal, 2005, p.332). The lack of reliability of the data, as it was copied from secondary sources is also acknowledged by Miles (Miles, 2004). Over the past fifty years, researchers have had “insufficient documentation” to discuss the special education needs and disability issues. (Alur, 2003, p.36). Educational research is not a high priority in India, leading to the difficulty in finding good published and academic work in international journals (Panda & Jangira cited in Singhal 2005). However, existing resources attest to the fact that this ancient and historically rich country has valued the education of its citizens since the 19th century. The initiatives to educate children in India, a ‘non literary society’ during the 19th century, through ‘no separate classes, no marks, no exams’ are documented in the literature (Miles, 1997, p.98). In other words children with disabilities were educated with typically developing peers in the past but they were not graded or tested for their education. Current literature on the Indian education system states that public schools in the country are for the poor and private schools are for the rich (Jha, 2007; Singhal & Rouse, 2003; Alur, 2003). Recent research highlights increased enrollment of children with disabilities to the public schools (Singhal, et al. 2011). These researchers who conducted the study in Madhya Pradesh, a state in North West India highlighted the fact that most participants in their study attended school with their main hope to earn a job up on graduation. However findings revealed that education did not help people with
disabilities with an employment. Thus few participants in the study were frustrated about their education. This qualitative study of thirty participant’s from North India reveals the need for government officials and policy makers to think about life of children with disabilities after graduating from high schools. Further most of the existing literature on people with disabilities in India comes from the northern part of India.

I decided to conduct a study in Kerala, a state in south west India as the progress made in the social sector has gained recognition at the national and international level. There is lack of literature that provides explanations regarding the state initiatives to include its children with disabilities in the public school system. The Kerala government website lists various changes and developments made by the state in the social sector, but there is no discussion regarding inclusive education for people with disabilities. If the Kerala state has not succeeded in providing equal education for all children with disabilities, she cannot claim herself as a state that is fully literate. If states like Kerala can eradicate the caste system, practices like child labor, and other issues like female infanticide that still exist in other states (Ramanathayyer & Macpherson 2000), why can it not institute inclusion? How can we use the same mind-set and determination to eradicate segregative practices for people with disabilities? Such an achievement would be a model for all India.

This ancient country needs convincing research information along with other developmental initiatives by the government. As parents are the main care providers of their children with disabilities, it is important that each of us learn about their daily life experiences. Moreover, in a country where caste system was dominant and is still prevalent, people being classified based on their socio-economic status, the attitudes of these families living in different situations can reveal rich data which could help other parents, teachers, professionals, policy makers and government officials in making future decisions.

This book will help you to understand the lives of parents who have children with special needs living in upper, middle and lower classes in India who are educated, less educated and uneducated. The author will inform you of the social, cultural, and educational attitudes towards disability derived through the voices of these families living in different socioeconomic situations. Further the effects on the opportunities and daily experiences of their children with disabilities in the south west of India – Kerala will be explored. The first chapter highlights the education system in India, lives of people with disabilities in the country and regarding a state in south west India, Kerala. The second chapter discusses the importance of education from an international perspective. In this chapter, the author briefly discusses history of special education in the US, international issues, discusses family values, culture and the current status of education in India and kerala. The third chapter discusses the story of a boy with cerebral palsy born in an upper middle class educated family, both parents are educated. The forth chapter narrates the story of another boy with Cerebral Palsy born in an upper middle class family, parents who are less educated. The fifth chapter discusses the story of a boy with Down syndrome born to middle
CHAPTER 1

class educated parents. The sixth chapter is the story of a boy with intellectual
disability whose parents are less educated, belongs to a middle class family. The
seventh chapter is another story of a boy with intellectual disability born to a lower
class family with parents who have completed only tenth grade. The eight chapter
narrates the story of another boy with intellectual disability born to two uneducated
parents in a lower class family. The ninth chapter discusses the research methodology,
tenth chapter discusses the major themes from all the stories and finally the eleventh
chapter recommends suggestions for future.
CHAPTER 2

EDUCATION FOR ALL AND ITS IMPORTANCE AROUND THE GLOBE

Education may be like a seed that is sown with great hope for better results. It is a tool for survival and helps a person in the “...creation and perpetuation of social identity” (Piddington cited in Ray & Poonwassie 1992 p.9). Access to education is a human rights issue and its importance has gained recognition at both national and international levels (Rioux 2007; UNESCO, 2006). It provides powerful leverage to reduce issues like poverty and inequality (Ray & Poonwassie 1992; World Bank 2008). It is also important to acknowledge that education can also be a force to maintain inequalities in societies (Apple 2006; Devine, 2004). While students in the lower socio economic status have less opportunities to succeed, students of the same age in the middle and upper class are getting lot more opportunities to succeed. Apple (2006) highlights the increasing costs of attending universities in the U.S. and its effects on the working middle class and upper middle class families. He also mentioned the increasing nervousness among many upper middle class families regarding their children’s future. When this happens in our communities at the upper class level, one can easily assume the situation of middle and lower class families. According to him, this trend is evident in countries like Britain. So I would like to acknowledge the power of education to build stronger communities as well as to maintain inequalities within societies. The reproduction of class by itself within societies through education is already recorded other researchers (Devine, 2004).

Education can equip a new generation and is primarily delivered through schools, which play an important role in our society. According to Rioux (2007), school systems are 'pillars of meritocracy' in any society (p.113). A robust education system helps in building a strong community, contributing to the development of a nation. Today international organizations like United Nations Educational, Scientific and Cultural Organization (UNESCO) and the World Bank have listed, as one of their millennium goals, the provision of primary education to every girl and boy child in the world with the primary objective of achieving ‘Education for All’ by the year 2015 (UNESCO, 2006; World Bank, 2000). To achieve this universal goal, almost 125 countries have signed the declaration proclaiming that every child has a fundamental right to education (Rioux, 2007). While the education and inclusion of all children have been successfully implemented and being practiced in many schools in the west, however they remain unsolved puzzles in many other countries around the globe. In other words, international initiatives and programs to include all children remain in print (i.e., policy documents or recommendations) while not
being implemented. This is particularly true for children and young adults with disabilities around the globe.

Today when countries around the globe, try to adopt inclusive system of education from the west into their home land, most of them forget the fact that it is not fully implemented in countries like the U.S. For example, some states like New York in the U.S. continue to have several special schools to educate children with severe disabilities. In other words, inclusion is still not happening for many children who have multiple and severe disabilities. So I agree to Slee who argues inclusion as “...troubled because its newfound respectability in policy texts and research programs appears to have attenuated its forces as a movement for educational reform” (Slee, 2008 p.99). Slee further acknowledges the fact that inclusion has focused on the struggles of vulnerable students, their right to access, participation and succession in schools. So it is important to acknowledge the strengths and weaknesses of inclusive education in any contexts.

**Special Education in the US and the Journey towards Inclusion**

Special Education is a system of education developed to educate children with special needs. Children with disabilities are educated using specialized instruction under this system. It is typically delivered in segregated settings in many parts of the world. In other words, children with disabilities are educated separately from typically developing children. Today, fewer segregated systems of education are seen in countries like the United States; instead, inclusionary education with a continuum of placement options (from the general education classroom to special schools, home-based, or hospital-based) can be widely observed. This was not true in the early 1900’s. The United States has a long history where people were segregated based on disability (Giordano, 2007; Winzer, 2002), poverty, color and cultural differences (Tyack 1974). Children with disabilities had limited access to education. They were a minority who were denied equal status in the society. The advocacy movements by parents contributed to the social change for people with disabilities (Yell, 2006). Today the emergence of special schools in the existence of inclusive schools supports that fact the philosophy of inclusion and segregation has its own strengths and weaknesses. So it is extremely important for us to take into consideration the voices and needs of people with disabilities, his or her families before enforcing an ideology into the lives of other people.

The civil rights movement is another major factor that contributed to the evolution of national special education legislation in the US (Smith & Kozelki, 2005). According to Danforth, Taff & Ferguson (2006), there was no American tradition prior to the mid-19th century regarding “…public care and education…” of children with disabilities (p.3). According to them, the professionals in this country adopted many approaches from Europe, especially the French methodologies. The initiatives taken by the French to include people with disabilities is well documented in the literature (Danforth, et al., 2006; Giordano, 2007; Winzer, 2002). Thus, it
is very important to note that the changes in the United States did not occur in a vacuum.

In 1975, the landmark legislation ‘Education of All Handicapped Children Act’, was passed by the US congress mandating all states to establish special education for children with disabilities across the whole country (Giordano 2007; Skrtic, 1991; O’dell & Schaefer, 2005; Winzer, 2002; Yell 2006). The passage of Public Law 94-142 brought change within the US and around the world (Margalit, 2000). Even after several reauthorizations, the basic foundation of the law remains the same, equal opportunity for all people with disabilities. The reauthorization of Individuals with Disabilities Education Act in 1997 and 2004 reaffirms the education of children with disabilities in regular education settings. The main purpose of IDEA is to ensure a ‘free appropriate public education’ with emphasis on special education and related services to meet the unique needs of children with disabilities, prepare them for “…further education, employment and independent living…” along with the protection of the rights of these children and their parents (cited in Yell, 2006, p.87). IDEA protects the rights of children with disabilities as well as the rights of the parents of these children. When the law mandated equal education for all people, there was less room for segregated education in the US education system. In other words, to be separate but equal is not acceptable and such education is considered ‘immoral’ (Heumann cited in O’dell & Schaefer, 2005).

Special Education: Culture, Family Values and Belief Systems. Internationally

To understand special education at an international level, one should understand the culture traditions and practices of people around the globe. Understanding the lives of other people, “…helps us become clearer about our own beliefs and values” (Sapon-Shevin, 2007, p.25). The importance of valuing culture in families and children with disabilities is well documented in the literature (Harry 1992; Harry, Kalyanpur & Day 1999; Kalyanpur & Harry, 1999; Lieberman 1990; Turnbull & Turnbull, 2001). Hence learning about culture not only helps us understand our own beliefs but also helps us to learn about the people around us.

Culture

Culture is a word derived from the French word ‘culture’ or the Latin word ‘culta’ and the word itself is older than the English language itself (O’Hagan, 2001). According to him, the original meaning of culture centered on earth and it’s soil. He also related the meaning of culture to tilling the land or improvement of a crop or its production. This meaning was expanded in the thirteenth and fourteenth centuries by including refinement or improvement of human beings mainly through education and training (O’Hagan, 2001). Tylor equates culture with civilization and defines it to be a complex term which includes “…knowledge, beliefs, art, morals, law, custom and any other capabilities acquired by man as a member of society” (Tylor cited in
O’Hagan, 2001). O’Hagan has included several definitions by different researchers in his literature. According to Hobbes, cultivation of minds in children happens through education (Hobbes cited in O’Hagan, 2001), so an educator does so through training at schools and colleges. Hence any educator who works with the minds of children or adults should be very knowledgeable about their students’ culture and practices. Failure to understand the culture can not only hinder development but can also cause damage to the future of the child. It is similar to planting a small seed into the soil. The planter should not only be knowledgeable about the soil, but also about all the environmental factors that are essential for the growth of that particular plant. For example, a cactus plant grown widely in the deserts of Northern India cannot be planted directly into soil in the US where there is a lot of snow. Similarly a lotus plant grown widely in the rivers in southern India cannot be planted directly into the rivers in the US. These plants will need special care, which includes the same temperature, soil, water and other environmental conditions that are present in India. Failure to make these accommodations can result in the damage, even to the extent of death of these plants.

Different Cultures

I recently observed a girl with Cerebral Palsy at a middle school in the United States. This child was born to an Indian family and raised in Canada. During my observation, I saw the teacher aide at the school fully assisting the child to use a knife and fork for the lunch. I noticed that the child was trying to eat the food using her fingers. The teacher aide responded to the situation saying, “No, keep your hands off”. The teacher aide grabbed a tissue, wiped the child’s fingers, cleaned her hand, and continued to encourage the child to use the utensils. Two days later, I visited this child’s family for dinner. We sat around the table for dinner together. I noticed that there was neither a knife nor a fork on the entire table. The father and mother of the child with a disability and her sibling, started to eat food from their plates using their fingers. I joined the group and started eating the food from my plate in the same manner, as I had no other option. I noticed that the child with Cerebral palsy, who was with us at the dinner table, used her fingers as well to eat the food, partially assisted by her father who was hand feeding. After the dinner, the parents carried their child with a disability into their bedroom using both hands, saying ‘my sweety will sleep with appa (dad) and amma (mom) tonight’. Before I left their home, I asked if all of them used fingers to eat their meals regularly. They responded, “it’s our culture”.

I consider human actions and culture as two sides of the same coin. As O’Hagan (2001) stated, “Culture is the distinctive way of life of the group, race, class, community or nation to which the individual belongs” (p.233). He considered it the frame of reference from which one’s sense of identity evolves. So, humans hold on to their culture and practice it irrespective of residing outside their community. This is very clear from the above scenario where the child even though she is a citizen of
Canada, holds and practices Indian culture and values along with her parents. From this example, we can see how important it is for us to understand the people around us. Understanding the lives of other people, “…helps us become clearer about our own beliefs and values” (Sapon-Shevin, 2007, p.25). According to this researcher, accepting the differences in people helps us value the experiences of others and acknowledge that “…we aren’t the center of the universe” (Sapon-Shevin, 2007, p.25). The importance of valuing culture in families and children with disabilities is well documented in the literature (Harry 1992; Harry, Kalyanpur & Day 1999; Kalyanpur & Harry, 1999; Lieberman 1990; Turnbull & Turnbull, 2001). Hence learning about culture not only helps us understand our own beliefs but also helps us to learn about people around us. There should be a reason for every human action, and many actions can be understood by using culturally appropriate lenses. According to some researchers, learning about culture is an ongoing journey: discovering and learning from people in different places (Kalyanpur & Harry, 1999). When it comes to the education of children in this globally changing society, there is no one country that provides the one best answer for the nature of the best schooling, the type of education children must receive or the responsibilities of the government (Peters, 1993). A cross cultural understanding about practices will also equip a person to work with people from diverse cultures.

All of these ideas about culture ultimately go back to the word’s original meaning relating to the earth and its soil. People who are born and raised in any land will always hold the values and cultures of that land over many other practices. This is evident even from the history of the American Indian tribes in the US, who considered their land to be their ‘mother’ and culture to evolve from integration with the earth, skies and nature around them (O’Hagan, 2001). Here you can see that people hold values and culture closer to their heart. This is clear from some of the human actions of Native Americans in response to white colonialism in the early development of the country, US. According to a researcher who observed the banishment of the Choctaw tribe from their Mississippi land, many of the people reached and touched the trunks of the tree prior to their journey (Debo cited in O’Hagan, 2001). This reveals the strong connection or attachment of human to nature and to his or her land. O’Hagan has discussed various other powerful cultural practices by the native people in his literature. He discussed the strong cultural relationship of humans to language, religion, family and practices of people from one country to another.

*Family Values*

A practice in one culture may not be appropriate or acceptable in another culture. For example in the United States, individualism is highly valued and this concept pervades the major education law, Individuals with Disabilities Education Act (Kalyanpur & Harry, 1999). According to Kalyanpur and Harry, individualism values self reliance, individual autonomy and maximization of one’s potential including competition in open employment. This practice is in contrast to the culture of many other countries.
In Asian countries ‘collectivism’ presides over individualism (Turnbull & Turnbull, 2001). Asian countries include China, Japan, Korea, Vietnam, Cambodia, Thailand, the Philippines, Malaysia, Indonesia, Taiwan, the pacific islands and countries of the Indian subcontinent (Bui & Turnbull, 2003). In a collectivistic society, a group is valued rather than an individual (Kalyanpur & Harry, 1999). A collectivistic group could involve parents, siblings, family members, professionals and people in the community. This collectivistic culture prevails not only in Asian countries, but also in communities that are African American (Kalyanpur & Harry, 1999; Logan and Willis cited in Turnbull & Turnbull, 2001), Native American (O’Hagan, 2001), countries in the middle east (Sharifzadeh cited in Turnbull & Turnbull, 2001), African tribes (O’Hagan, 2001), Tanzania in Africa (McGillicuddy-De Lisi and Subramanian in Kalyanpur & Harry, 1999) to name a few. In Africa there is a proverb that defines their culture, “…it takes a village to raise a child…” which the people consider an appropriate motto (Fowler, Ostrosky & Yates, 2007). In countries like Thailand, the education system itself was not designed to create independent thinkers (Carter, 2006).

Belief Systems

The birth of a child with disability is considered as: “…God’s judgment on the family…” in Mexico (Bauman & Lo, 2005, p. 26) and the result of past deeds in Asian American families (Chan, Fadiman, Rodriguez and Yalung cited in Bui & Turnbull, 2003), Thai families (Fulk, Swerdlik, & Kosuwan, 2002), and Indian families (Alur, 2001; 2003; 2007, Mullatti, 1995; Timmons & Alur, 2004). While this belief is strongly held by people, there are other communities that consider the birth of child with disability positively. For example, Hmong and Filipino families consider a child with severe disability as a sign of good luck (Harry, 1992). Similar belief regarding the birth of a child with disability as gift of god is also held by many Mexican American, African American and Tswana families (cited in Kalyanpur & Harry, 1999) and some Chinese-Thai families (Fulk, Swerdlik, & Kosuwan, 2002). There are also mixed perceptions in some countries. Interestingly, in Thailand where the Buddhist religion is practiced, people consider the birth of a child with disability to be good luck as well as bad luck. The Chinese parents of children with disabilities believe that they are punished for wrong actions committed in the previous life, while some Chinese-Thai families believe the birth of a child with Down syndrome brings the family good luck (Fulk, Swerdlik, & Kosuwan, 2002).

These diverse practices should be the foundations or platforms for building any new projects in these communities. When policy makers framed the ideology of inclusion, they forgot to consider culturally appropriate ways to achieve their goals in diverse communities around the globe. For example, after ten years the policy of inclusion still has not successfully gained a foothold in India. Everyone knows that it is a powerful tool and will yield fruitful results, yet people are still trying to figure out the barriers that have hindered successful implementation.
Education in India

Education was adopted in the Indian constitution as a “direct principle” instead of a right in the same year the country received independence, 1947 (Singhal 2006, Alur 2003). At this very time the United Nations General Assembly adopted Universal Declaration of Human Rights (Puri & Abraham, 2004). Importantly, directive principles are not legally enforceable as they are “…asserted as being fundamental in the governance of the country…” (Singhal, 2006, p.352). The efforts to make primary education compulsory and elementary education a right started as early as 1909 (Jha, 2007). According to Jha, it was by December 2002 that the government of India finally agreed to bring education as a new fundamental right. Jha quotes the law, “The state shall provide free and compulsory education to all children of the age 6 to 14 years in such manner as the state may, by law, determine” (p.126).

This ancient and historically rich country has valued the education of its citizens since the 19th century. The initiatives to educate children in India, a ‘non literary society’ during the 19th century, through ‘no separate classes, no marks, no exams’ are documented in the literature (Miles, 1997, p.98). Research also documents that people who were blind and who had physical disabilities were teachers in India in the late 19th century (Miles 1994). When it comes to education of people with disabilities, initiatives began in 1883 when a Christian missionary started the first school for the blind (Alur, 2003).

Special Education

As of 2009, it is 59 years since India received independence from the British rule; the country gained independence from the colonial education system where the British wanted “…a class of persons Indian in blood and color, but English in tastes, in opinions, in morals and in conduct” (Macaulay cited in Alur, 2003 p.20). This is the history of colonial education in India, where education was restricted to the ‘upper and upper middle class family’ (Naik cited in Alur, 2003, p.20). Current literature on the Indian education system states that public schools in the country are for the poor and private schools are for the rich (Jha, 2007; Singhal & Rouse, 2003; Alur, 2003).

After looking at the colonial system of education and current literature, I would state that Indians still follow a system that was left in the country by the British. Despite the passage of several laws to implement inclusive education, a government report in 1994 stated that ninety eight percent of the ‘disabled’ do not receive any care from the government (Alur, 2007, Timmons & Alur, 2004). It is important to remember that India is the second largest populated country in the world. There are several discrepancies in the data regarding the number of children with disabilities. A ‘best estimate’ by Rehabilitation Council of India (RCI) stated that there are 30 million children with disabilities in India (Office of Chief Commissioner of the State cited in Singhal, 2006). Timmons and Alur (2004) estimated a total of 50 million people who are ‘disabled’ or with ‘special needs’ (p.40). According to The Office of the
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Chief Commissioner for People with Disabilities (2003) cited by Singhal (2006), the existing data on the number of people with disabilities in India are highly unreliable. A total of 80 million children between the ages of 6 and 14 years are estimated to be ‘out of school’ (Department for International Development cited in Singhal, 2006).

Children with disabilities usually receive their education in special schools strictly segregated from the public school system. This is a reality in spite of the law ‘PWD Act’, where the state is to ensure free education for children with disabilities. Based on my experience, I would state if a person with disability is born to a poor family, the responsibility of care or education falls on the shoulders of his or her family. As Alur (2001) stated, “The institution of family and its value system emerges as the strongest agency for care” (p.290). The lack of technical or professional support forcing parents to care for their ‘disabled’ child is also mentioned by other researchers (Thomas & Thomas 2002). Alur also maintained that there is no welfare state that takes care of the needy, aged or children with disabilities.

Inclusion

Inclusive education is a phrase that has spread all over the globe after its success in western countries. Today, inclusion has gained several definitions: Ainscow (2007) defined it as “…a process…concerned with the identification and removal of barriers” (p.156). He further described inclusion as “… PARTICIPATION AND ACHIEVEMENT OF ALL STUDENTS,… A PARTICULAR EMPHASIS ON THOSE GROUPS OF LEARNERS WHO MAY [BE] AT RISK OF MARGINALIZATION, EXCLUSION OR UNDERACHIEVEMENT” (p.156). Other researchers have defined inclusion as a concept where children with disabilities are to be educated in neighborhood schools along with children without disabilities in general education classrooms (O’Dell & Schaefer, 2005). It is the legal system in the United States that changed the lives of children with disabilities. Most important are the roles played by parents, the advocacy groups and legislatures of this country, which largely contributed to achieving the educational rights of children and youth with disabilities (Winzer, 2002; Yell 2006). Thus, the opportunity to be equal and treat everyone equally is embraced from childhood in citizens receiving public school education in the US. Treatment of people equally varies from one place to another. According to Poonwassie, (1992), despite several dilemmas and contradictions, equal opportunity to education maintains that achievements will be made by the individual based on his/her ability if provided with opportunity. Equal opportunity for education paves the way for each and every individual to succeed based on his or her abilities in a natural environment with no restrictions. Inclusion is like a bridge that helps a person cross from childhood dependency into the harsher adult world, despite issues like inequality, injustices and any sort of segregation based on disability.

Inclusive schools focus on operating classrooms as supportive communities that include all students (Stainback & Stainback, 1996). To build a strong inclusive community, it requires the full support and participation of all the members in the community. Researchers have found that the inclusive system of education not only
benefits people with any disability, but also educates children without disabilities, resulting in positive outcomes (Giangreco, et al. 1993). It also strengthens larger friendships and reciprocal interactions among children with and without disabilities (Fryxell & Kennedy, 1995). As children at school come from diverse backgrounds, educating typically developing children on disability issues is very important. This type of education could help children who have ‘limited knowledge’ better understand the concept of inclusion and disability (Hodkinson 2007). It could also help prevent issues like bullying and teasing of children with disabilities, a concern that has been raised by Martlew & Hodson (Gray cited in Hodkinson, 2007). The ‘rude behavior’ in adults and children is also considered a barrier to inclusion along with other societal attitudinal barriers in countries like Canada (Pivik, Meamos & Laflamme, 2002). Negative behaviors will continue to affect children with disabilities in different settings, especially if people around them are unaware of the person’s abilities and are not educated about disabilities. I believe that these acts by typically developing children due to their limited knowledge are not only happening in Canada or in the US but are also happening in countries around the world. The success and effectiveness of this education system for the development of all children has been demonstrated in the West. Inclusion is the one and only best system that can include all children, promoting equality and social justice.

An ancient country, India, after being freed from British rule, adopted several laws and policies for its citizens with disabilities. As early as 1883, when a Christian missionary started the first school for the blind, initiatives were taken to help people with disabilities obtain an education (Alur, 2003). The word inclusion gained momentum in the Indian settings especially after the country became involved in international initiatives on inclusive education. The Salamanca statement is considered one of these significant initiatives (Singhal, 2006). By signing this agreement, India agreed to educate all its children with disabilities in regular schools with no segregation. However even today, inclusive education has no accepted definition in the Indian context (Singhal & Rouse 2003). It is considered to be an utopian ideology in India (Sen cited in Singhal, 2005). Moreover the terms “inclusion” and “integration” being used interchangeably by researchers in the Indian setting are also documented (Singhal, 2005; 2006; Kalyanpur 2008).

Current Status of the Law in India

India has enacted People with Disabilities Act (PWD) in 1995. According to this law, the state is to ensure free education for children with disabilities in ‘normal schools’ (cited in Pandey, 2004, p.29). Special schools (segregated), increased from 237 in the year 1966 (Puri & Abraham, 2004) to 2500 in the year 2000 (RCI cited in Singhal, 2006). The Ministry of Human Resource Development (MHRD) estimates that 1035 special schools emerged in India during the early 1990’s (MHRD cited in Singhal, 2006). This growth in the number of special schools clearly reflects the government’s lack of efficacy in implementing the laws for an inclusive system of
education. These inabilities of the government officials either to implement laws, sustain initiatives, or upgrade them to a national level has already been critiqued (Singhal, 2006). The flourishing of special schools all over India is an answer to the question of how interested the Indian government is in implementing inclusion. It is equally important to keep in mind that there are millions of children without disabilities that remain out of school due to various reasons. Assuming family responsibilities and contributing to family income at a younger age, could be one among several other reasons that children without disabilities leave or don’t attend school. However, when it comes to the education of people with disabilities, public school doors often continue to remain closed and special schools remain the only other option. The doors to special schools remain closed for those people with disabilities who cannot afford monthly fees or live in a remote place. That is, special schools are not able to include all children.

According to a government report in 1995, only 450 special schools receive government support for its functioning (Singhal, 2006). This leaves individuals or nonprofit organizations to find their own funding sources to run their organizations or special schools. Private organizations cannot be blamed for not admitting students who are unable to pay fees into their special schools. These arguments point out the negligence of policy makers or government officials who promote the growth of special schools, thus ignoring laws on inclusive education. These actions by officials have compelled citizens to adopt their own ways of bringing up their children with disabilities. Hence, families of children with disabilities have less faith in their legislation. This ineffectiveness of government to educate children with disabilities in schools or support them with care after they complete schooling causes parents to assume this burden.

Parents being forced to take care of their child with disability due to the lack of any other professional or technical support has been highlighted in the literature (Thomas & Thomas, 2002). Throughout India the majority of services for people with disabilities are delivered through nonprofit organizations. These operate mainly in urban areas, while seventy percent of Indians live in rural areas (Timmons & Alur, 2004). Further, as these schools charge fees, they are inaccessible to the poor. So it is very clear that education of a poor child with disability in an existing special school is nearly impossible. Children whether rich or poor in rural areas, have no access to any education. The majority of nonprofit organizations adopt a charity framework for services to children with special needs (Alur, 2001). Alur further comments that senior policy makers blame the failure of inclusion on the limitation of the culture and the belief systems.

The lack of understanding about inclusion, its goals, processes and motivation underpinning such efforts is still not understood by the Indian government (Singhal, 2006). Thus there is confusion from the top level government officials to the people at lower levels regarding the inclusive system of education. This confusion permits special schools to increase in number, thus taking away precious resources in the country, without solving the issue. I would not say that the Indian government is
not taking initiatives, but would state that they lack implementation or enforcement of initiatives to their full extent. Scholars like Jha & Alur have highlighted laws in India, providing few specifics for execution (Alur and Jha cited in Kalyanpur, 2008). These researchers have also commented on some of the mandates overlapping and contradicting one another.

When this confusion exists at the top level, we easily understand why the people at lower levels and charged with executing laws, are in a state of confusion. This is very clear from the literature. According to Kalyanpur & Gowramma (2007), the parents lacked information on their rights as well as information about the available resources for their children with disabilities. These researchers have further mentioned the absence of any services in rural places and the unsatisfactory services that were provided over time in those places. Misra, another researcher, mentioned the belief of families who choose not to educate their child with severe or multiple disabilities, because they believe education is not beneficial for their children (Misra, cited in Kalyanpur, 2008). I personally believe that these types of beliefs are very common and arise because the parents in these countries have no other choices. When a family cannot afford to pay fees and services are not available locally, they have no other option than to keep the child at home. I would argue that if the laws were enforced and the child admitted to the local school, this situation would not have been recorded. I support Sapon-Shevin who stated that exclusion hurts and creates a feeling that stays with one throughout one’s life (Sapon-Shevin, 2007). I would suggest enforcement of laws to be one of the most important steps towards inclusion. This should include opening local school doors to children with disabilities in the neighborhood and educating professionals and people involved in the community. I believe implementing laws can also help overcome existing barriers and attitudes among people within the whole country.

**Educating Professionals and Parents**

Teachers and parents in any community are considered to be key players in the education of children with disabilities. This is very true when it comes to an Indian setting. For example, In India, an individual’s personal choice becomes secondary over family interests. According to Kakar and Chowdhry cited in Srinivasan & Karlan, (1997), in an Indian setting, the lives of children are controlled and directed by the parents, to the extent of choosing professions and spouses for their children. In a culture where teachers play an important role in the student lives, it is important to educate them on inclusion which could help overcome the barriers generated by these professionals. There are several cultural barriers that have already been identified; negative attitudes (Kalyanpur & Gowramma, 2008), lack of formal training (Singhal & Rouse, 2003), charity frame work among teaching professionals regarding disability (Alur, 2003) are concerns that have been highlighted. The greater willingness of teachers to work with children with disabilities after training for successful inclusion has been discussed by a researcher that has been provide
in another country, “…Lao People’s Democratic Republic…” (Holdsworth cited in Kalyanpur, 2008, p.258). The need for educating parents and people with disabilities on their rights is another important factor for the smooth transition to inclusion. If parents of these millions of children with disabilities join hands together, there is no doubt that they will contribute to the change. People should realize that inclusion is not a favor; instead, it’s their individual right (Sapon-Shevin, 2007).

It is important to note that demanding one’s right is perceived as selfish, antisocial and is foreign to the majority of Indians (Kalyanpur, 2008). In such a country, there is need for education and future research. Education and research in this area can not only contribute to the change but could also help people join hands together, depending on one another, advocating individual rights making it easier and more acceptable in this culture. Therefore, I stress the need for parents and individuals to press for their rights instead of waiting to let other issues gain priority. Ongoing advocacy movements by individuals and groups can bring about changes. The power of advocacy movements to introduce changes to the field of special education has been proven in countries like the US (Yell, 2006).

Research carried out in India has highlighted disability issues being pushed to the bottom of the priority list in the legislation by issues like poverty, caste and gender in India (Harris-White cited in Alur, 2003). It is important to note that the government has not fully succeeded in addressing issues that took precedence over disability. This has left disability issues an unsolved puzzle in the whole nation. It is said that in India, anyone can start a school even under a tree (Kalyanpur, 2008). These acts of people show their determination to bring in changes to their community. In a country like India, where there are huge cultural differences from state to state, it is important to conduct a study in a state that is unique and has made outstanding progress in the social sector.

Exploring the State Kerala

Kerala is a state in the Southern part of India with a total population of 29 million people accommodated in an area of 38,863 sq.km. This is the only state in India, formally recognized as ‘totally literate’ and claims a population with the highest literacy rate in India (Chandran 1994; Ramanathaiyer & Macpherson 2000). Kerala has not always valued education or equality of humans. It was once called “the mad house of caste” by a Hindu reformer; Swami Vivekananda (Ramanathaiyer & Macpherson 2000, p.2). According to Ramachandran 1996, “…the worst forms of ‘untouchability’ were practiced in the Kerala state (p.274). In the past, people born to a lower caste were not permitted to access public places, temples or educational institutions. They were prohibited from taking jobs outside their castes, wear clean clothes, slippers or use metal pots or pans (Ramachandran 2000). Today, while other states within India still battle with the caste system, (Alur, 2003; Kalyanpur & Gowramma, 2007; Overland 2004; Ramachandran 1996; Thomas & Thomas 2002), any sort of caste discrimination is considered ‘a tale of the past’ in Kerala (Ramanathaiyer & Macpherson 2000, p.3).
The achievements in the social sector made by Kerala state are well documented in the literature (Dreze & Sen 1996; Mukundan & Bray 2004; Parayil, 2000; Prakash 1994; Ramanathaiyer & Macpherson 2000). Another outstanding unique feature of the state is that it is matrilineal, while other Indian states largely are patriarchal in nature (Alexander 2000; Ramachandran 1996). Kerala is also known as a state with no female infanticide and girls are considered lucky to be born there rather than in other states in India (Ramanathaiyer & Macpherson 2000).

While this state holds its head up with the pride of total literacy and claims to be a unique state, there is little or no discussion of her initiatives for people with disabilities and the families residing in the state. Puri and Abraham (2004) have mentioned that Kerala was the only state that showed remarkable progress when the nation initiated a new scheme to integrate people with disabilities. I believe the reason for this achievement to be due to the high literacy rate of its citizens. However, issues like dowry and religious belief are strong among the people just as in any other state. If a state like Kerala can eradicate the caste system, while practices like child labor, and other issues like female infanticide still exist in other states (Ramanathaiyer & Macpherson 2000), why has it not yet instituted inclusion? How can we use the same mind-set and determination that brought positive changes to Kerala, to eradicate segregative practices for people with disabilities? Such an achievement would be a model for all of India.

My three years experience as a director of a special school for children with disabilities and recent conversations with families and professionals in Kerala, reveal that special schools remain the major service provider for all children and adults with disabilities. Since the majority of special schools are in urban areas and these schools charge fees for their services, children from poor families and all those who live in rural places are left without any services. Families and people with disabilities are, in a manner of speaking, “left in a boat in the middle of the sea with no paddle or direction”. The reason why they do not join hands “to row together to reach the shore, or why people on the shore do not reach out to them” lies in deeply rooted tradition. The state with its desire to modernize society through legislation is confronted with a barrier of traditional societal attitudes and cultural practices. To my knowledge, no research has been carried out in Kerala to determine the precise nature of the causes of the state’s inattentiveness, in spite of its good intentions, to serve people with disabilities in segregated programs that aren’t inclusive. Thus, I decided to study the social, cultural, and educational attitudes towards disability in order to understand why there has been little forward movement in the effort to improve the lot of persons with disability in Kerala.