

HOW DO SOCIAL, CULTURAL AND EDUCATIONAL ATTITUDES TOWARDS
DISABILITY AFFECT FAMILIES OF CHILDREN WITH DISABILITIES AND THERE BY
AFFECT THE OPPORTUNITIES AND DAILY EXPERIENCES OF PEOPLE WITH
DISABILITIES IN KERALA- INDIA?

By

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To the Faculty of Washington State University:

The members of the Committee appointed to examine the dissertation of PAVAN JOHN ANTONY find it satisfactory and recommend that it be accepted.

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Abstract
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This study identifies the social, cultural and educational attitudes towards disability in the state of Kerala, India. Twelve individuals, parents of children with disabilities, living in different socioeconomic status and possessing different educational qualifications participated in the study. Qualitative data collected through in-depth interviews and observations were used for the research. In a society where people are classified according to their socioeconomic status, this research has revealed 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. The participants who took part in the study and their children with disabilities were not only unaware of their 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 participants have the common belief that their children will be dependent upon their parents or siblings for their entire life. Lack of opportunities in the community for people with disabilities is due to the lack of awareness among public about different types of disabilities. Implementing inclusive education is the only way to create awareness, bring in change and thus build an inclusive community.

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Dedication

This dissertation 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.

CHAPTER ONE

Introduction

“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. These issues vary from one country to another. Today when admission of children with disabilities to any public school is no longer an issue 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 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, all of whom, according to Mullatti, are “...converts from Hinduism” (Mullatti, 1995, p.13). 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. All over India, family is considered primarily responsible for its members.

Usually when a child is born into any family, he/she 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 God 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 special needs. In that situation, according to Puri and Abraham (2004), “The child is greeted with disappointment, frustration and anger” (p.22). According to Timmons and Alur (2004), “The Karmic theory of traditional Hindus about the present being a reflection of past deeds is strongly entrenched” (p.42). People strongly believe that the birth of a child with a disability is the result of a family’s past deeds. 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 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. Timmons & Alur (2004) have discussed how neighbors in the community approach families of children with disabilities with advice on "...who would be able to cure their child through certain medicines, about gurus and faith healing, of evil spirits being exorcised by witchcraft" (p.41). People with disabilities or their families at large are looked upon with sympathy and pity by a majority of people in the society. In a way, 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 within India, helping people with disabilities with money or other personal possessions are 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 an Indian setting. Helping beggars especially in front of religious places is considered a repentance for one's past actions.

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. 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 (Timmons & Alur, 2004). Today, while other states within India still battle with the caste system, (Alur, 2003; Kalyanpur & Gowramma, 2007, Overland 2004; Ramachandran 1996; 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). Kerala is also known as a state with no female infanticide and girls are considered lucky to be born there (Ramanathaiyer & Macpherson 2000). The education of children with disabilities 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 the rich and poor people. These gaps between people based on socio economic status can be observed in places like schools and job environments. Kalyanpur & Gowramma (2007) have highlighted the strong influence of the caste system in Indian society, relegating menial jobs (example: carpentry and shoe making) to a lower caste and positions of high standing to higher caste. Examples of high standing jobs would be bank officer, engineer, or doctor. Similarly in the education system, public schools are considered to exist for the poor and private schools for the rich (Alur, 2003; Jha, 2007; Singhal & Rouse, 2003). 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. Social inequality is considered an accepted value in 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 (Alur, 2003; Jha, 2007; Singhal, 2006). 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).

There is a lack of research that provides explanation for the status of inclusive education or equal opportunities for people with disabilities in the Indian setting. It is important to conduct a study in Kerala, 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 initiations 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 (Ramanathaiyer & 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. The struggle for me as a researcher to find good research or published journals in the field explains the need for further research. As parents are the main care providers of their children with disabilities, it is important to focus on conducting research on parents. Moreover in a country like India, where people are classified based on socio-economic status, an in-depth study into the attitudes of these families living in different situations can reveal rich data which could help policy makers and government officials in making future decisions.

This study will explore the social, cultural, and educational attitudes towards disability through the voices of families living in different socio economic 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. Finally, implications for future culturally responsive practices and policies will be discussed.

Operational Definitions

Socio-Economic

The government of India classifies its citizens based on their income. The two main classifications are Above Poverty Line (APL) and Below Poverty Line (BPL). According to the Government of Kerala website, every month the Government of India allocates Rice, Wheat, Sugar and Kerosene (fuel used to burn cooking stove) to the State Government based on this classification. This government document plays an important role in obtaining a majority of the government services for the people through out the country.

Upper Class Educated (UCE)

A family classified as APL by the government records and both parents are literate. They possess more than one private vehicle, land or building and pay luxury tax to the government. Both participants in this category have completed a Masters or higher degree.

Upper Class less Educated (UCLE)

A family classified as APL by the government records, both parents less educated. They own more than one private vehicle, land or building and pay luxury tax to the government. Both participants in this category are less educated, completed high school diploma.

Middle Class Educated (MCE)

A family classified as APL by government records and receiving services from government under that category. They are dependent on public transportation and both participants have completed a college degree or above.

Middle Class less Educated (MCLE)

A family classified as APL by government records and receiving services from government under that category. They are dependent on public transportation and both participants in this category are less educated, completed only a high school diploma.

Lower Class Educated (LCE)

A family classified as BPL by government records and receiving services from the government under that category. They are dependent on public transportation and both participants are educated, completed a high school diploma.

Lower Class Uneducated (LCUE)

A family classified as BPL by government records and receiving services from the government under that category. They are dependent on public transportation and both participants are uneducated.

CHAPTER TWO

A REVIEW OF THE LITERATURE

Introduction

Education is 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). 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 well built 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 World Bank have listed, as one of their millennial 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 practiced in some countries, 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.

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, segregated systems of education are no longer the accepted practice 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) are the recommended best practices. 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).

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 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 '*cultura*' 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 its 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 sweetie 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 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, Mccomas & 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 provided 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.

Theoretical Framework

I adopted critical theory to discuss my findings. Critical theory and its role in qualitative research is well researched (Gibson, 1986; Hinchey, 2001; Kincheloe & McLaren, 1994; 2005, Peters, Lankshear & Olssen, 2003). Gibson argues that all facts are socially constructed, determined and interpreted by humans; hence the changes are subject to human means (Gibson, 1986). The argument by Gibson was appealing to me. I believe that we live in a place that is created by humans with set rules and standards; it can be altered at any time by humans. I agree with other critical researchers who assume that "...all thought is fundamentally mediated by power relations that are social and historically constituted..." (Kincheloe & McLaren, 2005, p.304). According to Kincheloe and McLaren, critical theorists critique the scholarly work of researchers whose work is to adapt individuals to the existing world. Based on all these arguments by experts, I believe that the system has to change. In other words by adopting critical theory, I would like to understand the system in order to recommend changes. I acknowledge that changes do not occur in a vacuum, but processes can be initiated for the change through in-depth studies like this that involve rich lived and living experiences of parents of children with disabilities. Qualitative research that adopts critical theory can produce "...undeniably dangerous knowledge... that upsets institutions and threatens to overturn sovereign regimes of truth" (Kincheloe & McLaren, 1994, p.138), I strongly believe that the findings in my study

reveal such knowledge, thus contributing to the initiation of change in a system that has denied equal opportunity for children with disabilities for the last 58 years (time of Indian independence). I believe that stories of parents are powerful tools to be heard by policy makers or people in power who frame policies for people on how to lead their lives. I hold the common beliefs made by critical theorists. According to Gibson, critical theorists in education map inequalities in education, trace the source, and finally propose remedies to those injustices (Gibson, 1986).

CHAPTER THREE

RESEARCH METHODOLOGY

Introduction

Quantitative and qualitative researches are the two major research methodologies used in social sciences. Researchers use different types of data collection and analysis to conduct their studies in both these methodologies. For example, quantitative researchers rely on large number of subjects, study cases directly through random selection and use statistics, graphs and mathematics to present their findings (Denzin & Lincoln 2005). Qualitative researchers on the other hand study small numbers, develop a relationship with the subjects and present their findings without any measurement or experimentation. The main purpose of quantitative research is to generalize, explain causally and make predictions (Glesne, 2006). Qualitative researchers hold confidence in their rich data of individual cases, letting the reader make a “naturalistic generalization” (Stake, 1995; Stake & Trumbull cited in Stake, 2005). In other words, the reader tests generalizability in qualitative research. Readers can determine if the study speaks about their own experience or about other people they know. Further, stories in a qualitative study can also inform a reader about unfamiliar people and their lives (Ellis & Bochner, 2003).

Various reasons triggered my decision to do a qualitative rather than a quantitative research for my study on families and children with disabilities. My three years of personal experience working with parents and children with disabilities in India encouraged me to choose my career in special education. The day-to-day life experiences of the parents and the struggles of their children with disabilities that I witnessed motivated me to continue in this profession. This type of research helps understand a social phenomenon without disrupting a natural setting

(Merriam, 1998). By not disrupting the natural setting, a researcher is able to absorb the rich data with more accuracy than in a controlled research environment. This rich and thick description of data from a natural setting can help readers determine how closely their situations match the research, thus transferring the findings (Merriam, 1998). Since the life stories of people have always motivated me to think, learn, and understand about my fellow human beings, I chose this methodology for this study. Qualitative methodology answers questions like, “What is happening?” and “Why or how is it happening?” (Shavelson & Towne cited in Brantlinger, Jimenez & Klinger, 2005, p.195). I was curious to learn ‘*how*’ and ‘*why*’ families construct their lives in India and the impact of this construction on the daily lives of them and their children with disabilities.

As I studied the social, cultural, and educational attitudes faced by parents of children with disabilities, I considered qualitative research as the best methodology for conducting my study. This methodology helped me examine personal reactions, explore the beliefs, attitudes and opinions of people involved in special education including the general public (Brantlinger, Jimenez & Klinger, 2005). According to Brantlinger et al, individuals in small numbers need to be studied prior to the development of theories or hypotheses. In a country like India where there is lack of research, my study can help fuel the development of future large scale studies. This research methodology also helped me explore the nature and the impact of certain practices on families and their children with disabilities in settings where they reside, work, or are being educated (Brantlinger, Jimenez & Klinger, 2005).

In a country where family takes precedence over the government’s ability to care for or educate children with disabilities, it is very important to study the families and their experiences.

I believe families of children with disabilities are the best sources to gather data regarding the day- to-day life experiences of their children.

Case Study

I chose to do a case study from among the various other qualitative approaches to research. As stated earlier, my primary interest was to study families and children with disabilities in Indian culture. Along with my personal interest, I had to also take into consideration various factors such as the amount of time I could invest, access to the subjects, their availability and resources for conducting the study in a different country. After considering all these factors, I decided to use a case study approach. The main purpose of a qualitative case study is to gain an in-depth understanding about the cases.

The importance of understanding in-depth about a case through qualitative research is well recorded in the literature (Merriam, 1998; Patton, 1990; Stake, 1995; 2005). The case study method is a recommended type of inquiry for investigating social units that are complex, consisting of multiple variables that are important to understanding a phenomenon (Merriam, 1998). I used '*multiple case studies*' for my inquiry (Merriam, 1998; Stake, 1995) to understand the social, cultural and educational attitudes faced by parents of children with disabilities in India. Case studies can be focused on a "...person such as a student, a teacher, a principal; a program, a group such as a class, a school, a community; a specific policy; and so on" (Merriam, 1998, p.28). For this study, I chose six families from different socio economic status levels residing in the state of Kerala, in southwest India. I believe that families that vary in terms of their socio- economic status function differently as complex units and demonstrate several variables that change from one family setting to the other. I consider qualitative case study inquiry as the best strategy for my study, considering the various factors mentioned above. This

research also reflects an ethnographic study, as it describes people in a foreign country practicing different cultures (Glesne, 2006).

Case studies are conducted not to primarily understand other cases. I looked at my cases in-depth as they play "... a supportive role, and it facilitates our understanding of something else" (Stake, 2005. P.445). According to Stake, an instrumental in-depth case study helps us pursue interests that are external to our case. Instrumental case study requires cases to be chosen, I purposely chose six families for my study. This type of sampling is called '*purposeful sampling*' (Patton 1990; 2002). A purposeful sampling is used mainly to study rich cases (Patton 1990; 2002). According to Patton, a great deal about issues of central importance to the research can be learned from this type of sample. The families from different socio- economic backgrounds contributed to a wide range of experiences, as each of them leads a different life-style within the Indian society. Thick description of multiple case studies can also help readers determine how closely their situations will resemble that case. This type of sample also helps discover, gain insight, and understand similar cases in different situations (Merriam 1998); thus, increasing the likelihood of transferable results.

Participants

This study focused on six families of children with disabilities that differ in socio-economic status, and reside in the state of Kerala, southwest India. The father and mother of children with disabilities for this study possess differing educational standards and are purposefully selected. The families were selected with the help of a nonprofit organization that has been serving people with disabilities in the community for over twenty years. The socio-economic status of the families is classified according to government records. Except for one child, all other children with a disability were receiving services from this nonprofit

organization. All the participants resided in the nearby community. The age group of these children with disabilities ranged between 15 and 21.

Procedures

Participants selected with help of the non profit organization were contacted by the researcher via telephone for an informal conversation. Upon initial contact, the participants were screened to make sure they met the criteria for the study: age, type of disability, willingness to participate, socio economic status and documentation of disability. With the permission of the participants, the researcher verified the copy of the government records at the non-profit organization that stated the economic status and educational qualifications of the participants. The date and time for the interview was scheduled according to the convenience of the participants. The primary researcher traveled to the participants' geographical location, for conducting all the interviews and observations. The interviews were conducted separately with the father and the mother of the child with disability at their individual houses. The child with disability was observed at the home setting.

Prior to the one-on-one interview, the researcher explained the study and asked the participants to sign a human subject consent form approved by the Washington State University Institutional Review Board, which satisfied all components of the human subject research project (See Appendix A). All the human subject forms were translated word to word from English to Malayalam, native language of people in Kerala. Prior to the observation, children older than seventeen years of age were asked to sign the consent and assent form.

Data Collection

Interviews and observations were the primary sources for data collection. The interview consisted of previously developed open ended questions (See Appendix B) that reflected the

research objectives. The body language and personal space of each participant was observed and recorded during the course of the interview. As the study was conducted in another country, high importance was given to linguistic differences. All the interviews were conducted in Malayalam, which is the native language of Kerala. As any native language is demanding, a great deal of care was given to find the right word while translating the language (Vygotsky, cited in Siedman, 2006). A translator was hired for translating the interviews from spoken Malayalam to a written format and then to English. Anecdotal notes of observation were made during the course of the interview. The child with disability was observed at the home setting during the day of interview. For accuracy, summaries of transcribed data were shared with the participants in reading in the native language. The participants had the opportunity to add more information or edit the information if needed. A thank you note was sent to all the participants for participating in the study.

Data Analysis

The method of analysis is grounded in my own data (Glaser & Strauss, 1967). It is essentially inductive and reflexive in nature, where the theory emerges from the data rather than from a predetermined focus (Patton, 1990). Many of the overall themes, which are significant to this study, emerged from coding categories generated through the interviews and observations. These initial coding categories were further reexamined and analyzed. A cross case analysis of the data was completed. Patton (1990) explains cross case analysis as “grouping together answers from different people to common questions or analyzing different perspectives on central issues” (p.376). This method also includes “constant comparison” (Merriam, 1998, p.159). Cross case analysis results in themes emerging inductively from the data. These themes

were pulled out from the larger data set to better understand the phenomena that are being studied.

CHAPTER FOUR

Results

Introduction

This chapter includes a discussion of the various social, cultural and educational experiences and attitudes towards children with disabilities from childhood to their current teenage years. These experiences about past, present and future plans have been shared by the parents of these children living in Kerala, southwest India. A total of twelve participants took part in the study. Out of a total of six families, two families were below the poverty line; two families belonged to the middle class and two families to the upper class. The classifications of these families were based on governmental records and set criteria. Six participants, one couple from each classification, possessed a higher degree of education than fellow participants in their respective group. The participants who were educated and belonged to the upper class are identified as upper class educated (UCE) and those people who were less educated are identified as upper class less educated (UCLE). Similarly the educated people in the middle class are identified as MCE and the less educated as MCLE. Lastly the educated people in the lower class are identified as LCE and the uneducated as LCUE. All the fathers of children with disabilities are identified as 1 and mothers as 2. See Table 1 for a summary of participant's demographic information.

Table 4. 1 Participants family demographic information

Name of the participants	Educational background of parents	Societal Status as per governmental records	Belief System	Type of disability in the child(school records)	Type of disability according to parents	Name, age and sex of the child with disability	Sibling
UCE 1 UCE2	Bachelors Bachelors	Upper Class	Christian	Cerebral Palsy	Nil Walking problem	Titi - 20, male	1 older girl
UCLE1 UCLE2	10 th grade 10 th grade	Upper Class	Muslim	Cerebral Palsy	nerve problem brain problem	Shawn - 20, male	1 older girl & 1 younger girl
MCE1 MCE2	Bachelors Masters	Middle Class	Hindu	Down Syndrome	Down Syndrome	Unique - 15, male	1 younger girl
MCLE1 MCLE2	9 th grade 5 th grade	Middle Class	Muslim	Mental Retardation	Brain problem	Saad – 17, male	1 older boy
LCE1 LCE2	10 th grade 10 th grade	Lower Class	Christian	Mental Retardation (twins)	Sick children	Alaas and Vilaas, 16, male	1 younger boy
LCUE1 LCUE2	Below 5 th grade	Lower Class	Muslim	Mental Retardation	Brain problem / sickness	Dahas – male, 19	1 younger girl

UCE- Upper Class Educated; UCLE- Upper Class Less educated, MCE- Middle Class Educated, MCLE – Middle Class Less educated, LCE – Lower Class Educated, LCU – Lower Class uneducated, 1 – Father of the child with disability, 2 – Mother of the child with disability

Upper Class Educated: UCE1 and UCE2

UCE1 and UCE2 live in a small town two miles away from the city in a modern two storied house. There is a big living room, one dining room, small kitchen and four bedrooms. The researcher noticed a television set in three bedrooms and in the living room. There was a computer instead of a TV in one room. UCE1 runs a business in the nearby city and UCE2 takes care of the household. Both of them are former college graduates. They have two children: an older girl is finishing up her Bachelors degree in Computer Science and the younger boy (Titi), who has Cerebral Palsy, stays at home. UCE1 doesn't think that his son has any disability and UCE2 defined the disability in her son as a walking problem. Titi uses a walker to move in and around the house. He is fully dependent on his parents for travelling places and according to UCE 1 and 2 they bought a car mainly for his transportation.

The family related that their son was born in a private hospital in the neighboring city. After delivery, baby Titi was placed in an incubator for four days. UCE1 and UCE2 noticed their newborn son cried continuously after birth. According to UCE1, there were a couple of days when he and his family members were holding the baby and walking for long hours in the hospital hallway to stop the baby from crying. During this time the doctors did not communicate either to UCE1 or UCE2 regarding any developmental delays in their newborn. After 24 days they took Titi to a pediatrician in another hospital. This time the new doctor labeled him as "... a case of retardation." The doctor told UCE1 that the brain of the child was damaged due to the fits and this was the reason baby Titi cried continuously. The family started treatment for fits on the 29th day, gave medicine to Titi for three years and did not notice fits after that. UCE1 and UCE2 then tried several treatments for Titi other than using western medicines. They tried Ayurveda – a treatment using herbs, Yoga – physical exercise, massage, physiotherapy and surgeries. Titi

was taken to several leading specialists in the country seeking a cure for his developmental delays. This included consulting doctors from the west. UCE1 shared "...I did not care for money, I was ready to go to any extent... if my son can be like any other person of his age". When UCE1 was asked for his opinion whether the people in lower socio economic class could afford such treatments, he said: "I don't believe that Titi is having any deformity. If that is so, I have deformity. I'm not able to reach the range of great people in the world. It doesn't mean that I have deformity. It is because I have different abilities...I don't think that Titi has any deformity." According to UCE2 most people who belong to the lower socio economic class will not be able to do similar ongoing treatments for a child with deformity due to the high expenditure.

UCE1 and UCE2 further discussed their belief system. They shared that they were Orthodox Christians. At the entrance of their house and in the living room, they have framed pictures of Jesus Christ on the wall. According to UCE1 and UCE2, they go to church regularly and talked about their daily family prayers in their living room where they have the framed picture. UCE1 shared that his son's birth was a case of "cord wound," and he believes it to be the result of past deeds. He told the story of his great grand-father, who once destroyed a temple where people worshiped snakes, and he believes that the cord wound around his son's neck was the snake's revenge for the past deed of his great grandfather. UCE1 further shared that his family members brought, for several years, offerings to the Hindu god as repentance for his great grandfathers' action. UCE1 claims himself as a person who believes in Bible. He also strongly believes that "... we have to suffer for our past deeds during our coming births". UCE2 doesn't believe in past deeds or Karma. She stated: "I believe in prayer...when we pray, God shows us the way for doing the right things..."

When it came to education, regular schools denied admission to Titi. School officials told UCE2 "... he is not able to walk, there is a chance for other children to knock him down..." and denied admission. UCE2 shared the general educator's response "...it would be difficult to take care of a sick child... in the general education setting". UCE1 pointed out the lack of infrastructure at regular schools to accommodate any children with a deformity as another reason for the denial of admission. Both UCE1 and UCE2 were unaware of any laws and policies on inclusion or about their son's individual rights in Indian society. Titi has never received any government support or benefits. The parents have never tried to inquire about the services from the government for their son during the past 20 years. Titi received education in a special school for almost twelve years. UCE1 and UCE 2 are not satisfied with the special education services at the school, especially during his teenage years. UCE1 defined education in a special school as:

"...there is a prayer in the morning and some exercises are practiced, then some lessons are taught according to the interest of teachers,...they eat food and sleep for some time and then leave school... is not getting anything from that school according to his age and capabilities...Titi said that he doesn't want to go there."

Titi has been staying home for the past five years. Since Titi has great interest in cars and computers, UCE1 took him to a neighboring car repair shop where Titi could spend some time. Lack of transportation facility for Titi on a daily basis and absence of toilets at the shop compelled Titi to stay at home. Since he is interested in playing with computers, UCE1 hired a person to teach Titi computer at home, but the trainer had to leave after a month when he found a new job. UCE1 then tried to get admission for Titi at the local computer institutions;

unfortunately, all seven institutions in their neighboring town were accessible only by climbing stairs. This along with lack of disabled-friendly toilets in those buildings prevented Titi from developing his computer skills. The parents could not find any other instructors to home tutor Titi. In the absence of a new trainer, Titi started spending time himself playing with the computer at home for long hours. He played with my laptop and taught me shortcut keys that I had never learned before. He operated programs and shared the purpose of software on the laptop that I had never used. I was surprised to see the skills in Titi. He wanted me to talk about Microsoft Vista on my laptop and compare it with Windows XP on his computer. I was not able to answer some of his technical questions related to computer operation. I asked Titi to explain the technical terms he used for conversation and he gave me several examples using his desktop computer.

UCE1 shared an incident when their car broke down and was taken to the repair shop. When the mechanics couldn't figure out the fault, Titi went in and shared his knowledge on how to fix the car. The car was fixed and UCE1 realized that his son learned that skill from the internet. UCE1 mentioned that he had to disconnect the internet connection as he received a huge bill from the local service provider. UCE1 shares that he is sad because he is not able to help provide his son opportunities to use his intellectual capabilities. He further shared:

“...I told Titi about starting a computer centre and I was ready to provide maximum help possible, but there are limitations. I have always tried to provide him with treatment to bring him to a better stage. I am satisfied to some extent, because he shaves, goes to the toilet and dresses by himself...activities of daily life, he performs by himself.”

UCE2 shared the strengths in her son. She described Titi as a person who has lot of abilities and someone who is always eager to learn new things but there are very few opportunities. Since Titi has been staying home for the past five years, UCE2 is concerned about her son not being able to "... walk or play or interact with other children of his age. He has a craze for vehicles and he loves to drive. I'm very sad that he cannot do it and all his desires are not fulfilled" UCE2 excused herself, shed tears and walked into another room and came back after a while.

Titi used to attend all the public functions. UCE2 shared that Titi has started avoiding public as well as some family functions. She thinks that nowadays he is more aware of himself as a person with limitations. UCE1 and UCE 2 do not consider Titi a problem, but UCE2 shared that Titi feels uncomfortable being in public, outside the home setting. Titi gets to go out with his parents for movies or shopping once in a while. UCE1 has to support Titi to climb stairs and in most places shopping is impossible for Titi, and he stays in the car. If Titi decides to stay home for some reason, UCE2 or her sister stays with him. Both UCE1 and UCE2 are unsure about Titi's future. UCE1 has registered some family property in the name of Titi to secure his future. UCE1 believes that his older daughter will take care of Titi, while UCE2 is unsure what will happen after her daughter's marriage. In Indian culture the girl usually leaves her family and joins the boy's family. UCE1 and UCE2 also shared their plan to find a groom for their daughter who might be willing to stay with their family after marriage. UCE1 also shared his plans to find a suitable bride for Titi. However UCE1 is unsure if he will be able to find someone who is willing to get into a relationship with a person like Titi. UCE2 asked me "How can we trust any stranger to take care of Titi?..."

UCE2 thinks that there has been a lot of change in attitude of the people in Kerala society. She tells about the past: "...50 years back when people in Kerala would see a mad person, they would throw stones at him and make him run, mainly old people and respectable personalities would take charge of such things, but today's society doesn't do so". UCE1 believes that changes did not happen due to governmental initiatives; instead he gives credit to the media or movie makers. According to UCE1 there are chances for change, if "...a good government comes into power..." UCE1 shared that "... he has a soft corner for people with disabilities in his heart..." UCE1 admits that he helps strangers who have disabilities with rides and helps financially only because he understands how difficult it is for anyone to have a deformity and live with it. According to him, he learned it from taking care of his son. So according to him societal changes could happen only through awareness and education. Both parents support inclusion but are still unsure about its effects in Kerala society. They strongly believe that parents and siblings are the ultimate care providers for anyone with a disability in Indian society.

Upper Class less educated: UCLE1 and UCLE2

UCLE1 and UCLE2 live in another small town in a newly built two storied building. According to them most of the furniture and fittings inside the house were imported. UCLE1 runs businesses in the neighboring state and UCLE2 takes care of children at home. UCLE1 comes home once every three months, for 2-3 days or when there is any special occasion. He talks to his wife and children on a daily basis. They have three children; the older girl is married and stays with her husband in a neighboring town 10 miles away. Their second son (Shawn) has

Cerebral Palsy (CP) and attends a special school fifteen miles away, and their younger daughter attends the local public school.

The family owns a private vehicle and according UCLE1 and UCLE2 the main usage of car is to take their son places. The family is not dependent on public transportation for traveling. There are four bedrooms, one living room, dining room and a kitchen in their house. A picture of mosque and a proverb, “Yasin” is framed on the wall in their living room. Shawn looks at the picture on the wall and says “Allah”, Muslim god. Shawn has his room upstairs and gave me a tour of the whole house as soon as I arrived at his house. He crawls inside the house to move around and wanted me to sit in his room and chat. He showed me his new cell phone and the different features in it. According to him, it was a gift from his dad. Shawn’s room has an air conditioner and a television set with cable connection and a DVD player. There were two other television sets in their home. He has been going to the special school for almost thirteen years and is still attending the same school. Shawn’s parents have been paying a monthly fee for transportation and schooling for all these years. Shawn shared with me during the brief chat that he is tired of school but does not have any other options to learn a life skill or spend time at home.

According to Shawn’s parents, he was born in a private hospital in a bigger city in the neighboring town. UCLE2 had a normal delivery and they left for home the same week. The doctors did not communicate regarding any developmental delays in their newborn. UCLE2 noticed that her sister’s son who was born on the same day as Shawn had many skills that she couldn’t notice in her son. UCLE1 and UCLE2 noticed that their son was not able to lift up his head, roll over onto his back or side or make any sounds like UCLE2’s sister’s child. By the

fourth month, UCLE1 took an appointment with another doctor in the neighboring state where he ran businesses. The doctor told him that their son had some nerve weaknesses. According to UCLE1 the doctor said: "...during the delivery time perhaps there would have been a delay in baby coming out... in that holding nerves would have broken..." UCLE1 believes that it is the fault of the doctors and states "...they hide it from us". According to UCLE1 if doctors

"... had shown a little patience, it would not have happened ...sometimes doctors were not even present and nurses would have attended it, it may happen. Since we were not in the labor room, we don't know what had happened. Anyway, there is no appeal in the fact that it is due to the mistake of people at the hospital..."

According to UCLE2 the doctors informed her about a cyst in her stomach and the chances of having some complications during the delivery of Shawn. UCLE2 was upset about the fact that the doctors did not communicate about any deformity in her new born. The disability in Shawn was identified only after four months by another doctor in a different state. When UCLE2 shared the new doctor's finding with the doctor and hospital officials who supervised Shawn's delivery, they denied the same saying "... nothing similar is recorded...". UCLE1 described the whole system as "...corrupt...fraudulent...inhumane". Both parents admit that things have changed in hospitals since that time especially with the advancement in technology.

All the relatives and grandparents of Shawn expected a cure for his disability. UCLE1 and UCLE2 started several treatments hoping for a cure, including Ayurveda, Homeopathy, Yoga, Massage and physiotherapy. Shawn was taken to several doctors around the country. They switched several medicines and tried various treatments. UCLE1 and 2 shared that they learned

from experts that their son's disability cannot be cured. However they recently provided Shawn with a nine month long massage treatment. The center that offered this massage to Shawn promised UCLE1 and UCLE2 that the therapy would cure the disability in their eighteen year old son. This treatment that was provided in their home state lasted for a period of nine months. Shawn had to stay at the center by himself during this period of time. The parents were not permitted to reach Shawn during the time of treatment. This was a rule at the therapy center. UCLE2 visited her son once in a month on a weekend. The family spent over 3000 US dollars which is almost 150,000 Indian rupees for this treatment. Shawn was 18 when he underwent this treatment. Shawn had severe body pain after the treatment but his condition remained unchanged. He shared that the people at the center used lot of force for stretching different body parts, and that the procedure was painful. During the day of the interview, while UCLE2 was sharing this therapy, Shawn interrupts the conversation and says "... ente ammo njaan avide eni orikkalum pokilla" which means, "...Oh mother I would never go there again...".

UCLE1 and UCLE2 are strong followers of the Muslim religion. According to UCLE1 and 2 they practice their religion and offer prayer on a regular basis. UCLE1 shared that Shawn observes fasting during the month of Ramadan without any one's advice and participates actively in all the religious festivals. Neither UCLE1 nor UCLE2 believe that their son's birth is due to any karma or past deeds. In fact UCLE1 believes that his son's birth brought him good luck. He shared that he was able to expand his businesses and reach his current status in society after the birth of Shawn. UCLE2 shared the belief system among neighbors and other older people in the community who believe that her son's birth is a result of past deeds. UCLE1 also considers birth of a child with disability as "... a shock treatment...or a test by God... to remind everyone to care for each other..." According to UCLE1 and UVLE2 Shawn is well accepted by people in the

neighborhood and community. However, they think that everyone has sympathy and pity for him. However UCLE2 shared about the difficulties they faced while trying to find a suitable groom for their older daughter. She shared that several marriage proposals from many families were denied to her older daughter as she had a brother with disability.

School officials denied Shawn admission to three local public schools, according to UCLE2, because of his inability to walk. Both parents were unaware of the laws and policies on inclusive education. Twenty year old Shawn and his parents are still unaware of disability rights for an Indian citizen. According to UCLE2 Shawn was denied financial help from the government, as he was classified as a person above the poverty line or belonging to the upper class by governmental records. Shawn has been paying monthly fees for receiving special education services from a private special school for the past thirteen years. In the special school there are children from the age of four to twenty four and above. Shawn tells UCLE2 about his disinterest in going to a special school. He asked, "Now what is the use of going there, I don't know anything, I have grown up, what will I do along with these children going there?" UCLE2 asked another question in response to Shawn's question "...what will I do with him, keeping at home..." She knows that her son is bright and intelligent, but cannot find any opportunities in the community or in the neighborhood. It takes over two hours for Shawn to get to the school that is 15 miles away. He is dependent on a school van operated by the special school to travel to the school and back. The one way journey to the school takes two hours in a packed van with over 70 other children with disabilities. Shawn communicates his school activities with his parents on a daily basis. UCLE1 shared an incident when one of Shawn's class mates had financial difficulty and was skipping lunch at school on a regular basis, Shawn asked him to help his

peer's family financially. After thirteen years, the routine of travel in a packed van and education with young children still continues for Shawn in the absence of other age appropriate training.

UCLE1 and UCLE2 are very supportive of the special school and its services. According to UCLE2 it is the only school that caters to the needs of children like Shawn in that entire county. They are unaware of any other education system. UCLE1 and 2 did not know about any rights for a person with disability in the Indian setting. They were unaware of their son's right to a free appropriate public education or about the concept of inclusion. According UCLE1 he is financially capable of supporting his son's daily needs. He believes that if money is deposited in the bank for any child with disability, their future after the demise of his/her parents is somewhat safe. UCLE1 further stated, "...If such children have no parents, it is equal to their death... the future...will be very miserable... my opinion is that if the child is not from such a family, when the parents die, they should also be killed..." UCLE1 believes in change, but does not think it will come soon through the government. He urged the need for parent associations to come forward and advocate for their children's rights. According UCLE1 government officials can bring in the change through good programs (packages). He thinks the future of children with any disability can be secured if the government supports them via special investment schemes or insurance plans that will secure their future. However, UCLE1 thinks that government officials have little interest in these issues, "...they don't have time; they have only their own time. Because during the time of election, they give promises to people by telling we will do this we will do that. But during the 5 years, they will not do anything. They act according to their personal interests". To UCLE1's and UCLE2's knowledge, the majority of services for people with disabilities in the state are catered through private nonprofit organizations. According to UCLE1, God has created individuals who have passion to serve people with disabilities, and they

are the ones who run these organizations. The parents of Shawn think that in the absence of these organizations, their son would not have had any chance to go to a school or receive education on a regular basis. After hearing about the inclusive system of education and its benefits, both parents advocated for its implementation. They have no trust in the government's promises. Shawn joins the conversation when UCLE1 talks regarding governmental authorities, he said "Oh brother they will only speak...nothing will change... people like me will sit at home... poor will suffer... nothing will ever change". Shawn addressed the researcher, "brother". In Indian culture, it is not polite to call an older person by his or her name. The researcher used the words Uppa (dad) to address UCLE1 and Umma (mother) to UCLE2 throughout the communication.

UCLE2 shared that she would have advocated for her rights on inclusion if she was aware of this earlier. According to UCLE2, she is not worried about her son's disability after observing a number of other children with varying disabilities at the special school. She thinks she is fortunate that her male child has disability and not the female. She said, "If I had a daughter at the age of Shawn I would be greatly tensed. Will I be able to go out keeping her alone at home? We cannot arrange someone to take care if it is a girl. Since it is a boy, I can go out peacefully... we cannot trust anyone... Parents have to strictly take care of them... will never have peace of mind if we go out after leaving the female child at home... [our] future will be miserable..."

UCLE1 and UCLE2 are unsure about the future of Shawn. They are searching for opportunities for Shawn outside of the special school setting. UCLE2 shared about the whole family members' interest in finding a bride for Shawn. However, she is unsure about the

practicality of such a dream in the current Kerala society. UCLE1 shared his plan to deposit money in savings for Shawn. He thinks that the monthly interest will help Shawn take care of his expenses. However UCLE1 is worried if strangers or other relatives "... may intend to kill him and take the income. So, we cannot trust any one. We cannot trust relatives and our own people in this matter". UCLE1 and UCLE2 are not sure if Shawn's sisters will take care of him as they will be married off to another family. UCLE1 thinks that it will be a "bonus" if one of his daughters and her husband would take care of Shawn after the demise of both him and his wife. Today UCLE2 stated that Shawn has started avoiding attending public functions. UCLE2 thinks he is becoming more aware of his limitations and shared an incident during Shawn's sister's wedding where Shawn refused to be on the front stage with other relatives. Shawn will soon be 21 and for him he will have the same routine of special school and home.

Middle Class Educated: MCE1 and MCE2

MCE1 and MCE2 live outside of a small town in a newly built house with two children. The older boy (Unique) who has Down syndrome goes to a special school four miles away from home, and their younger daughter goes to a public school in the neighborhood. MCE1 is an electrical engineer and MCE2 works part time at a local computer training center. Both of them graduated from college, MCE1 earned a bachelors degree and MCE a masters. Their home has three bedrooms, one living room with dining area, and a kitchen. Unique shares bedroom with his younger sister. There is a small pooja (prayer) area attached to the living room with statues of Hindu gods and goddesses. Before my visit they had lighted lamps in front of the statues and told me that they light the lamps and offer prayers at home on a daily basis. They do not have a

private vehicle and are fully dependent on public transportation for travel. According to MCE1 and MCE2 they hire a taxi if they have to travel with their son to far away places.

Unique was born in a private hospital in a neighboring town. The doctors told MCE1 that his son had Down syndrome soon after his birth. The doctor advised "...these are the features of the disability and for God's sake, do not do any medication...because this is a problem...of the chromosome formation at birth time...he is going to be slow...everything is going to be delayed by at least two or three days...love him more than anything else and give special training". MCE1 worked in Dubai, a country in the Middle East. Unique spent his days in Dubai from the age of three months old to 6 years. MCE2 related that she took him to a crush (child care) in Dubai when Unique was eighteen months. Unique spent two hours a day interacting with typically developing children in that setting. When Unique was three years of age, he started attending a regular school in Dubai. He started learning the alphabet, numbers, months and pictures on a chart with children of his age. After a year, MCE2 started taking Unique to a special school two days a week, while he continued regular schooling. Since the special school charged fees for services, it became unaffordable for MCE1 and MCE2. This compelled them to stop special schooling for Unique before the end of one year. Unique then attended a Montessori school for a while. Unique and his parents returned to India when he was six years of age. MCE1 and MCE2 very much liked the overall education that was provided to Unique during their time Dubai. According to MCE1 he learned many daily life skills like toileting, brushing his teeth, dressing, packing the bag for school and keeping things neat and tidy. Both parents agreed that he developed a very good routine in his daily life. Later, after receiving advice from a medical doctor, MCE1 and MCE2 decided to have a second child. The doctor advised them to have another child, so that Unique would have a sibling to support him

during his older years. The parents believe that Unique and his younger sister have a very good relationship. MCE2 shared her frequent advice to her daughter: "...you should look after him; he is not able to do everything. I have a brother who has hearing impairment. He has normal intelligence. Still he has his own problems. I tell her: 'you are seeing me helping my brother; like that you should look after your brother'... we are nurturing such a feeling in her mind. I wish that at least she will be there to support him when we are not alive".

After returning to India, Unique was denied admission to the local public schools in Kerala. MCE1 and MCE 2 had already inquired about the availability of local special schools in their home town prior to their travel back to Kerala. MCE2 feared that the lack of trained professionals in regular schools would not be able to handle Unique. She also had the fear of lack of security in regular public schools. She thought that one of the local public schools with unlocked gates might not be a safe place for Unique. MCE2 also worried about Unique hurting his peers at regular schools. They received admission for Unique at a local special school near their home town. Unique is dependent on a school bus to travel to the school. According to MCE1, "in his 8-14 years of age he has not learned anything...he is still there what he learned from Dubai..." However both MCE1 and 2 admit that there were changes in Unique that they noticed after they returned to India. The one most notable change in Unique was the frequent interaction with people in the native language, Malayalam. Unique's tendency to run out of their apartment room without notice was no longer an issue after their return to Kerala. He stays home with no prior direction and the parents think that he has more freedom in the Kerala home setting. According to MCE2 Unique spoke English at school and Malayalam at home. He lost his skill of speaking English after his return to Kerala. MCE1 is not satisfied with the services at the local special schools. According to him "...the children come in, sit, play, eat and return

home. He is concerned about the efficacy of training provided to people who want to be special educators. The frequent change of staff in the school is another concern that was raised by both the parents.

MCE1 views his son as a young adult like any other person with the only exception that Unique learns at a slower pace. MCE1 and MCE 2 were unaware of any laws on inclusive education or about the rights of their son with disability. MCE1 inquired at the local government offices regarding the laws and policies for people with disabilities. He shared: “I have inquired about this particular law. I haven’t seen anything in writing..., I approached the school officials...Panchayat...nobody could provide me any details”. Panchayat is a government office. In other words, the local government officers could not provide full information regarding the laws and policies on disability issues to MCE1. According to MCE1 the local government receives funds for distributing to people with disabilities, however the local leaders do not know about the appropriate use or distribution. He blames the political leaders for the failure to implement laws; he considers the majority of the leaders uneducated and lacking any concern for their fellow humans. He said “the country is governed by politicians and run by bureaucrats... most of them are not properly educated. Unfortunately, our politicians as a whole are drop outs from colleges and schools, most of them, probably 10 or 20% will be from a good ...When the politicians themselves are not educated...they don’t know human values, they don’t know the basic.....you know..... education. They don’t know how to behave. They have no concern for human beings; they have no concern for the society. They are the people who are making our policies...”

Unique continues to attend the special school. This active young boy is fully dependent on his parents to travel outside the home. MCE1 and MCE2 both support the inclusive system of education. However, they doubt its implementation in a society like Kerala's. They believe that changes can happen if the state elects new educated leaders into power. MCE1 acknowledges the Marxist government's initiative to most of the developments for minority people in the state. However, he thinks they forgot to consider people with disabilities in their political agenda.

MCE1 and MCE2 do not think that their son's birth is due to any past deeds. According to MCE1 it is Unique's Karma. He further said that he is an engineer by profession because it's God's Karma. MCE1 and MCE2 are unsure of Unique's future. MCE1 thinks change will come about through education, which according to him is given by God, while MCE2 expects her daughter to provide lifelong care for her son.

Middle Class less Educated: MCLE1 and MCLE2

MCLE1 and MCLE2 live in a village 20-30 miles away from the main town. They have three children: an older boy, who just graduated from high school, their second boy (Saad), who has mental retardation and attends a special school in the main town, 20 miles away, and their youngest daughter, who is enrolled in the local elementary school. According to the parents, their younger boy has some problem with his brain. Neither parent had completed their tenth grade. MCLE1 manages a store in front of their house and MCLE2 takes care of the household. They have two bedrooms, one living room and a kitchen in their house. Saad, seventeen years of age, sleeps next to his parents and at times shares a bedroom with his brother. In the living room, a proverb from the Muslim Bible, "Yasin" is framed on to the wall. The older son of MCU1 and MCU2 said that it is a prayer from the Quran. MCLE1 owns a motorbike that he uses

mainly to transport his younger son to school and back. They avoid long distance travel with their son with a disability, because of the lack of private transportation.

Saad was born in a city hospital thirty miles away from home. The delivery was normal, and he was not diagnosed with any developmental delays by the professionals. After a year his parents noticed that their son was not able to grasp things, sit by himself, or show other signs of developmental skills expected in children his age. This led MCLE1 and MCLE2 to consult a doctor for advice. The doctor did not identify any problems with Saad and told the parents that "...Saad is ok and things will get alright by themselves...". The doctor further told the parents "...Valarumbam Shariyaakum..." which means he will be cured as grows up. MCLE1 had a lot of hope in the doctor but lost faith when he did not notice any change in Saad after another year. According to MCLE1, Saad started to walk by the age of four. It was then the doctor advised MCLE1 and MCLE2 to find a special school for Saad's education. MCLE1 remembers Saad was a handsome child at the time of birth, and says "...I still adore him...but I am mentally worried about him, as he is not like any other children of his age. We are sad since he is like this. It was God who gave him to us, so we have to look after him till death". MCLE2 shared that her son has good skills; he recognizes familiar faces and greets people around him with a big smile. MCLE2 was very quiet during this interview, answered questions in one sentence or using a word. She wept several times during the course of the conversation, talking about her son.

MCLE1 and MCLE2 are strong believers of the Muslim religion. According MCLE1 he attends mosque and offers prayer on a regular basis. As Muslim women are not permitted in the mosque, MCLE2 offers prayers at home. During the interview, MCLE2 wore a traditional Muslim black dress with the whole body and head covered. Before answering each question she

looked around, and she signaled her husband and mother-in-law to sit in the same room during our conversation. Both parents do not believe that their son's birth is due to any past deeds. MCLE1 stated that "...our families haven't done any faults. I consider it as a test of God. I believe that God gives such children only to people who can care for them. God considered us like that and thus gave him to us...we look after him in the best possible way". MCLE1 shared the negative attitude of a few people in his neighborhood and society who share their thoughts that his son is the result of his family members' past deeds. When MCLE1 was asked about his approach to people he said "...avar aa padichu vechathu anganeyangu paadam..." which means they will continue to sing what they have memorized. He further shared that he pays little attention to such comments. He strongly believes that his son will have a closer place with God in heaven as "...he does not have the intellectual ability to distinguish between right and wrong...an innocent being..." MCLE1 wiped tears and asked me for a break and to have some coffee and bread. The interview continued only after the food.

Saad was denied admission to the local public school. Both MCLE1 and MCLE2 were unaware of any laws and policies related to special education. Both parents support inclusion; however, they are unsure of its implementation in a place like Kerala. After learning about the inclusive system of education, MCLE1 shared that officials fail to implement laws, and people in the society still fail to seek their individual rights in the court. He thinks that people like him, who have a son or daughter with disability, are fearful of going to the courts to get admission for their child in regular public school, because the school officials might oppress such children in those settings forcing parents to remove their children with special needs from the school. MCLE1 and MCLE2 also fear the lack of security in public schools, unlocked gates, and absent individual attention. They also highlighted their worry about poorly trained teachers at public

schools, especially in the context of educating children with disabilities. Saad has never received any financial assistance from the government. MCLE1 believes that his son did not receive any assistance from government because of the "... laziness of government officials". MCLE1 was told by friends and other parents of children at the special school regarding financial assistance from the government. He said, "...some panchayats allotted it. But our municipality hasn't taken any initiative to deliver that benefit ...I tried a lot to get that money...but the officials were of less help.... I feel that both the governmental authorities and political parties don't have goodwill to make proper use of such benefits. Central government had allotted this fund to all panchayats and municipalities at the same time. Although the few other panchayats have delivered it to children with disabilities, it has not been given to any child in our municipality. Still now, we are trying to get that money personally and with the help of the school. It would be a great thing if we could get assistance for his studies...."

MCLE1 believes that government can bring in change, but he feels there is a need for more advocates and professional organizations to come forward to compel officials to enforce laws. Saad is now 17, and continues to attend the special school, where he started his education. MCLE1 shared that Saad discontinued his education for almost two years due to his continuous crying while at school. According to MCLE2, she discontinued sending him to school as he was not eating any food there, thus she hand fed him at home. MCLE1 and MCLE2 are happy with the special education services. According to MCLE1 there is no other school in that area that admits children like Saad who have a disability, and provides them with education. MCLE1 is not fully satisfied with Saad's education services and progress he has made at school. He said that "...since there is no other option, I sent him there. I'm very sad that he is not able to do things like dressing or going to toilet by himself at this age. He hasn't got any training for doing

such things from school. We had requested the teachers to provide training for doing such practical things. But that is not happening. He is also not ready to do things by himself. When his stubbornness increases, it becomes difficult for us to do such things for him... he eats by himself at school... sometimes teachers hand feed him...at home he is always hand fed...”. MCLE1 and MCLE2 say that Saad is fully capable of eating by himself. Saad eats with partial assistance and at times by himself when he attends public events or in places like restaurants. He rarely seeks help with hand feeding at those places. However both of them are unsure about how things will be in upcoming days. They firmly believe that their older son will take care of Saad through out his entire life after their demise.

Lower Class Educated: LCE1 and LCE2

LCE1 and LCE2 live in a colony, away from a big town. LCE1 is a painter and LCE2 takes care of the household. LCE2 also works part time as a helper at a nursery school in their neighborhood. Both of them have completed tenth grade. A colony is a place where several people buy small pieces of land and build homes in a limited area. There is a small courtyard and the house is small compared to other participants' houses. There are lots of houses that are built close to one another. A small fence made out of plants serves as a boundary between their house and the neighbors. They have three children; the two older boys (Alaas and Vilaas) are twins who have mental retardation and the younger boy attends the local public school. The twins attend a special school 20 miles away from home. LCE1 and LCE2 classify the disability in their children as '*sicknesses*'. The participants often mentioned that their children were "...Sughamillatha Kuttikal..." which means "...children who are not well..." The family have a small nice home with two rooms and a kitchen. The home is made of brick and is not plastered.

There were several small posters of Jesus, the Virgin Mary and various saints up on the wall in their small living room. LCE1 and LCE2 consider their living room to be their daily prayer room and dining room. LCE1 and LCE2 are proud that they live in a Christian neighborhood. They are fully dependent on public transportation and avoid most travel plans due to their children's disability.

Alaas and Vilaas were born in the nearby public hospital. It was only by the eighth month that the parents realized that they were going to have twin babies. According to LCE1, doctors shared that one of the babies could not be rescued and so the father would have to sign some papers. LCE1 signed the papers but was not aware of their contents. However, his wife gave birth to the twins and had no complications. According to LCE1 a yellow color was seen on Alaas's body the third day after the delivery. As doctors at the hospital interpreted it as a clotting of the blood, he was shifted to the intensive care unit at another hospital, while LCE2 and Vilaas stayed home. Alaas stayed in the hospital for two weeks for his treatment. As both Alaas and Vilaas were getting sick very often, they were taken to the hospital on a regular basis. Alaas started to walk only by the age of five and Vilaas by the age of eight. Both of them had speech difficulty and none of the professionals communicated to LCE1 or LCE2 about their children's disability. LCE1 and LCE2 understood that their children were sick; at the time of the interview both of them classified their children as sick. When LCE1 and LCE2 noticed delays in their children even at the age of eight, they consulted a new doctor at a new hospital. LCE1 shared, "They were admitted in that hospital and stayed there for 2 weeks to do different tests and scanning. Doctors told me that my children could have been made alright if they were tested a little earlier, or if they were in their early childhood and now they will just grow up and will act

accordingly... We got a discount while paying the bill as we showed our ration card...” A ration card is a government document that shows the income of a person.

Alaas and Vilaas stayed home till the age of eight. By that time, the doctors advised them about education in special schools. So they got admission at a school that is 20 miles away from home. Alaas and Vilaas take the special school bus for travel to school and back. According to LCE1 and LCE2 one of them has to stay home if either of their two children gets sick or decides not to go to school. Alaas shows interest in going to school, while Vilaas stays back home very often. LCE1 and LCE2 shared that they are strong believers in Christ. They believe that Vilaas has recently started going to school only after their regular prayer to the Virgin Mary and also due to their recent visit to a famous Pilgrim center that is 100 miles away from home. LCE1 sees the birth of his children with disabilities as a gift of God and thus he is “...unable to reject the gift...”

LCE1 and LCE2 were not aware of any of their rights, as parents of children with disability, nor are they aware of the inclusive system of education. However, LCE1 shared that “...they are getting the pension for people with disabilities from the government on account of brain or low intelligence quotient... the electric post (electricity supply) here was sanctioned to us in their names after we submitted an application showing their certificates given by doctors. Earlier there was no electric connection for us.”

Alaas and Vilaas were denied admission to the local public schools due to their communication problem. LCE2 thinks that “...they will not go hand in hand with those children. Then, I feel bad when others panic seeing them. So, I don't like to send them to a regular school...” LCE1 and LCE2 support the inclusive system of education but are unsure of its

implementation in their home state. According to LCE1 "...they don't sit properly like other children. They have their own style. We don't have any issue with taking them to a regular school. However, if we take them to a regular school, they tell us that such children cannot be admitted here and there are special schools for them, seek admission there...general educators say 'other children will be in trouble (pick up negative behaviors) if they learn with them. Also, the other children will start observing them and it will affect their studies'..."

Both parents like the education that their children receive at the special school. However, they are struggling to pay the monthly fees for transportation and tuition. According to them, a lot of money is being spent on a regular basis for their medicines. They also spoke of Vilaas staying home without attending school on a regular basis. "This leads one of the parents to stay home, leaving them to live on the income of one person. LCE2 thinks Vilaas is lazy and doesn't like school, unlike Alaas, who is always happy to attend school. LCE2 thinks that walking with Vilaas to the school bus stop is similar to "...taking a cow to the butcher. There is pushing, pulling and tugging while we take him there. He cries aloud all the way. Seeing this, people will ask why send him if he doesn't like to go. If he becomes very stubborn, then those days we will not send him there". They shared how their neighbors were willing to look after their children once in a while during emergencies. When the special school is closed for the weekends, holidays and religious festivals, Alaas and Vilaas stay home with the parents. At times they spend a period of one month at their mother's house in a neighboring town. LCE1 and LCE2 do not travel long distances, go to nearby towns or to places with their children due to transportation issues. According to LCE2 the public stares at her children as if they haven't seen such children. She shared an incident when a girl child in their neighborhood, who is of the same age as her children got scared and cried loudly for help from the public when her twins tried to smile and

greet her using their limited communication from a distance. According to LCE1, he was able to build his home only with the help of neighbors and relatives. All of them look at us with sympathy and pity for being the parents of two '*sick children*'.

LCE1 and LCE2 are unsure about their children's future. At the age of 16 both Alaas and Vilaas sleep next to their parents and cannot spend a day by themselves. Both parents are hoping that their younger son will take care of his two siblings in the future. Both parents are considering the option of getting their children admitted to an institution where they can spend rest of their lives. In such a situation, LCE2 thinks that she will spend the rest of her life at the institution with her children, where she hopes to work part time. LCE2 cannot think about spending a day without her children. LCE1 shared him being mentally worried about his children. Both parents believe that God will open a door and secure their children and family.

Lower Class Uneducated: LCUE1 and LCUE2

LCU1 and LCU2 live in a colony, away from a big town. They have two children, the older boy (Dahas), who has Down syndrome, attends a special school in a town 20 miles away from home, and their younger daughter, attends the local public school. Both of them are unemployed. LCUE1 shared that it is Allah (Muslim god) who takes care of them through each day in the absence of a permanent job for him and his wife. There were two rooms in the house and a kitchen. Their house is not plastered and LCUE1 shares that they don't even have money for their daily living. There were several paper cuttings of the mosque that were pasted to the wall at the entrance of the house. According to LCUE1 and LCUE2, it is their god. They are fully dependent on public transportation and avoid travel plans outside their town or district due

to their son's disability. During the time of the interview, three of their relatives stopped by to see the researcher.

Dahas was born at a nearby public hospital, which is 3 miles away from home. The delivery was normal and LCUE2 stated that her son was a beautiful, nice, healthy baby. At the age of one Dahas had fits, thus his parents took him to the hospital. Doctors promised LCUE1 and LCUE2 they would treat and fix their child's fits as quickly as possible by giving medicines. However Dahas continued to have fits after a period of eight months. This time they consulted another doctor, where they repeated scanning and few other tests without checking the previous scanning records. This time the doctors shared with LCUE1 that "...the brain development is happening slowly in Dahas due to the fits in his early years and hence medicine should be given continuously...". LCUE1 and LCUE2 believe that their son has a disease that can be cured. However LCUE1 shared what the doctors told him "...this disease cannot be cured by giving medicines". Today when his son is 19, LCUE1 thinks that 80% of his son's misbehavior at home is due to his disease and 20 % is due to laziness. He also believes that his son's brain has stopped developing.

Dahas at the age of four was admitted to a regular public school. However, after six months the general educators were not willing to have Dahas in the classroom. They told the parents that "...all other children are learning progressively, you should take him to some other school, he is not getting anything." At this point, their medical doctor advised LCUE1 and LCUE2 to admit their son in a special school. So they got admission at a special school 20 miles away from home. After twelve years of special schooling by paying fees for tuition and transportation, when the family was no longer able to afford the fees, they decided to let him stay

home. During this time, they received an offer to admit their son to another special boarding school with lower fees, 40 miles away from home. So they admitted him to the new school. Dahas was able to visit his family once a year. After a year, Dahas was not willing to go back. He screamed and yelled when parents asked him to return. According to both parents, whenever they take Dahas on a bus and travel in the route nearer to that boarding school, Dahas immediately recognizes the route. On these occasions, Dahas refuses to get out of the bus until the parents assure him that they are going to a different place for a different purpose. Dahas returned to his old special school for daily education after returning from the boarding school. LCUE1 thinks his son is very bright. Dahas has memorized the name of all the professionals who have seen him. For example, he remembered the researcher who worked with Dahas five years ago. He remembers the researcher's name after five years. He remembers important dates, places and people.

Both LCUE1 and LCUE2 are strong believers in the Muslim religion. LCUE1 offers prayers at Mosque on a daily basis, while LCUE2 offers prayers at home. The parents shared that Dahas goes to the mosque only once in a while. He follows others' actions at the mosque. LCUE2 shared that her son offers prayer on a daily basis during the holy month. Both of them do not believe that their son's disability, or in this case the disease, is due to the past deeds or karma. LCUE1 compares his son's disability with other students attending special school and thinks his son is far better. LCUE1 believes the disease in his son is gift from Allah. He further shared his belief, "...if anything more serious than this comes...we will tell it to God...For instance if my hand breaks, I will tell it to God...for example no one says my name right, but my son did at the age of one...it is God's will..." This strong believer still gets worried at times and reacts to his son's behavior. According LCUE2 her husband drinks alcohol on a daily basis. She

shared about days when her husband threatened to kill her son by giving him rat poison. Dahas reacts to such situations by breaking glasses and plates. LCUE2 further shared about his son acting appropriately and working hard at school, but not being able to see such practices at home. LCUE2 wept in front of the researcher, wiping the tears and shared about some earlier days "... neighbors have beaten him once for playing with their children's toys without permission... my brother burned him with an iron rod for hitting his mother... neighbors at my mothers place once asked to beat him to death or to tie down and put in a mental hospital when he shouted and screamed...kill him... once a shopkeeper slapped him when he took a purse on sale without our knowledge, but we paid...". LCUE2 shared these few experiences and bursts into tears. She shared that people, especially in the neighborhood, have beaten him several times, whenever he tried to hold children. However, Dahas is always around children, holds them and plays with them in school and also while visiting his relatives. LCUE2 shared that for the past six months he has not been beaten by anyone, but shared about LCUE1 severely beating Dahas if he does any mischief.

Dahas and his younger sister have a very good sibling relationship. LCUE1 shared that his daughter does not know about her brother's disability, but LCUE2 shared that Dahas' sister always gets upset and cries when her brother is sick or misbehaves. Both parents were unaware of their rights, laws or policies on inclusive education or related to disability. LCUE1 and LCUE2 support inclusive system of education. They wish for that type of education for their son, but doubt its implementation in their home state. LCUE1 and LCUE2 think a special school is the best and only place where a child with disability can be safe and educated in the current system. They shared their wish about learning about their rights when their son was young. They also think being poor, they cannot advocate for their rights. According to LCUE2 "...who will listen

to us...we are poor...”. According to the parents, Dahas receives a monthly pension of one hundred and forty rupees (almost three dollars) every month. The parents received the amount once in six months, but the monthly fees for tuition and transportation come to more than ten dollars a month. LCUE2 shared about few letters that she received from the special school recently asking her to pay fees on time, or to discontinue Dahas’ education. On the day the researcher was present, she told about his interest to get married and how the parents responded to him positively asking him to be a good boy to get married. Both parents told me that their son can never get married but will be under the care of someone. They are unsure about his future. Both of them want their son to learn a vocational skill but cannot find a place where he can be employed. The parents were also hoping their younger daughter will take care of their son. LCUE1 is leaving things for God to decide.

The Social, Cultural and Educational Attitudes towards disability

Social

The themes surrounding social attitudes emerged from past and current day-to-day experiences. Irrespective of the participant’s diverse socioeconomic and educational status in the society, they addressed common themes about their lives with a child with disability: misleading advice from medical doctors, legal knowledge and governmental support, the general public’s view about disability, current status and future of a child with disability in the state of Kerala.

Advice from Medical Doctors

Medical doctors play an important role in the life of the general public all over India. Usually doctors are well respected and considered to be the most knowledgeable people in their field. Usually people in the society do not question most of their doctors decisions, instead, follow them hoping for better results. The doctors through out the country have private practices at home after their regular hours in a private or public hospital. Through out the state, it's the pediatric doctors who treat the children for any diseases or delays. So for many parents, pediatricians or medical doctors who treat their child from birth are in a way considered the god fathers of their children for health related issues.

The medical doctors influenced all the parents in the major decision making process regarding the lives of their children with disabilities. Ten out of the twelve participants shared that the doctors who assisted with the delivery of their child did not communicate with them regarding any developmental delays in their newborn. All participants did not know the exact diagnosis of their child's symptoms with the exception of MCE1 and MCE2. They mentioned that the doctor, who assisted with delivery, discussed with them that their son had Down syndrome and that they should "...love him more than anything else..." All other participants came to know about the disability in their child when they noticed developmental delays, leading to consultation with new doctors. LCE1 and LCE2 considered the disability in their son to be a disease, LCUE1 and LCUE2 interpreted it as a disease, MCLE1 and MCLE2 called it a brain problem while UCE1, UCLE1 and UCLE2 named it a nerve or brain problem and UCE2 a walking problem.

All the participants in my study received initial advice from medical doctors regarding the education or training of their child with a disability. They were advised to take

their child to a special school. However, this advice did not come immediately, but only after several years from a new doctor. Two of my participants, LCE1 and LCE2 were told by new doctors that their twins could have been cured if the disability had been identified earlier. Their children have Down syndrome. Two other parents, UCLE1 and UCLE2 were told that the disability in their baby was due to the doctor's carelessness at the time their of child's birth. This communication style not only upset the parents but left them in a situation with less hope. The parents that belong to the lower socioeconomic class felt, "... we are poor...what can we do? ...god will help us..." According to one participant UCLE1, the failure of the doctors to communicate effectively is "...a big fault or mistake..." All the participants have tried more than one type of treatment in their child hoping for a cure for the disability. The participants in the poor family admitted their inability to spend money for multiple treatments. The participants in the upper class family experimented with treatments like allopathy, ayurveda, massage, Yoga, and homeopathy. They took their child with disability for several treatments; they are still willing to spend money if their children can be cured. The family doctor advised UCE1 and UCE2 to "... spend money for the child expecting no return..." while UCLE1 and UCLE2 mentioned that they spent money expecting a cure. MCLE1 and MCLE2, parents of a three year old child with mental retardation were told by a doctor that their son will grow out of the disability. They are still waiting for that day although their son is now 17 years old. MCE1 and MCE2, educated parents of the middle class, decided to have a second child after listening to the advice of a doctor who stressed to them the need for a '*companion*' for their child with disability.

It is unclear if the parents were able to follow the medical language used by doctors, interpreting the meaning and understanding disability in their children incorrectly. On one hand the parents were hoping for a cure in their child while on the other hand they were unsure about

the real problem. There is a state of confusion among the parents, especially among those who are “less educated” and the “educated poor” about choosing the right path for their child with disability based on the advice of medical doctors.

Legal knowledge and governmental support

Education is the fundamental right of every child in India. According to the Indian law, each state endeavors to provide free and compulsory education for all children until they complete the age of 14 years (Jha, 2007; Alur, 2003; Singhal, 2006). According to the Indian constitution, 26-31 of the Persons with Disabilities Act (PWD), the local government authorities are to ensure free education of children with disabilities in appropriate environment, promote “...integration... in the normal schools...” (cited in Pandey, 2004, p.29). In other words it’s the right of a child with disability to receive appropriate education in a regular public school in the country.

All the participants were not only unaware of any of the laws and policies in special education but also had no knowledge about their individual rights. While free appropriate public education is the right of every child in India, all the children with disabilities were denied admission to their local public schools. The public schools offer free education but limit the admission to typically developing children. None of my participants were aware of their child’s right to this free education but they did try to get admission in their local schools. The schools denied admission to the children of all my participants based on the disability of their child. When the participants were informed about inclusive education, all of them supported such a system of education. However, they had less faith in government officials implementing similar

laws in Kerala. They believed that the government has the power to implement them if they would take the issue seriously.

MCE1's son with Down syndrome received education in an inclusive setting in Dubai. Since his son has been in Kerala for the past nine years, receiving special schooling, he advocates the need for inclusion in the local schools. According to him "... local schools should admit students with disabilities...government has to fund it ... the children coming to the school do not have to pay the money..." He further mentioned the need for government buses to transport these children to school and back home free of cost if needed. All the participants mentioned that the public schools in their neighborhood are at a walkable distance.

All the participants who have children with disabilities aged 15 to 20 years, neither received an education nor any other information on the current laws, policies or disability related rights for people with disabilities in Indian society. The three participants in the upper class families never tried to inquire about their rights or about any other support from the government for a child with disability. UCLE2 once applied for financial help for education of her child with Cerebral Palsy but was denied support due to their socioeconomic status. She considers the government's decision to be an inappropriate practice. Besides submitting applications for government support, four participants of the middle class did not receive any support or any responses to their application. MCE1 shared several attempts to get support, but according to him local government officials were unaware of properly utilizing the funds and had no records on disability related data in their offices. MCE1 responded about the laws and policies for people with disabilities, "... I cannot find anything in writing...I did ask school officials several times...government officials...there is nothing..." After several of these efforts MCE1

considered the government officials to be corrupt and thinks that "...their interest is just to make a buck out of it...the funds are received, whether it has been used...not used, they are not interested." MCLE1, another parent who has less education, thinks that the government officials have less interest in children with special needs, as parents continue to spend personal money for the care and education of such children. He urges the need for professional organizations, parental groups and schools to raise their voices and help parents seek their rights. He thinks individuals who approach government offices are not always treated well by the officials and they might respond differently to a group of people or associations.

The four participants of the lower class receive a monthly pension of three dollars per month, which they consider to be of great help. They shared that the pension amount is delivered every six months and so the total lump sum helps cover a few immediate needs. Both families spend over ten dollars a month for tuition and transportation. LCUE1 and LCUE2 related that their son skipped school several months in the past, as they were unable to pay monthly fees. LCE1 is unsure about alternate ways to support his children if his health is affected, and he cannot work.

General public's view about disability

According to all my participants the general public has no awareness about disabilities in children whatsoever. The people in their neighborhood approached them with pity and sympathy for being the parents of a person with special needs. UCLE2 shared her experience where many marriage proposals for her elder daughter were turned down because of the disability in her son. UCE1 commented that the negative attitude of people towards disability has changed drastically compared to the practices that existed 50 years back. UCE1 believes the change has happened

mainly through the influence of movies and the media, not government. As an example of experienced unawareness on the part of the general public, MCE2 told of how strangers frequently asked about her son with mental retardation, "...what do you do with him? how do you do his things [how do you help him?] and how is it [done]? ...many people ask me when they see Unique whether he talks or not... When people first see him, they think that these children cannot do anything. They can do a lot of things. But in general, people around us view him in a sympathetic manner saying he cannot do anything..." Since two of the children with disabilities belonging to the upper class family use private vehicles for transportation, they had less interaction with people in the public compared to others in the study. When it comes to the people in the lower class family, LCUE2 related several incidents where her son with disability was beaten up by the public for his misbehavior. According to LCUE2, people don't take time to understand such children. She related the incident when a shop owner slapped her son and accused him of being a thief instead of a person with disability for picking up a product he liked without his parent's knowledge. LCE1 and 2 said that people in their neighborhood are always willing to help their twins with mental retardation. However, LCE2 shared that there are people and children in the same neighborhood who refuse or are not comfortable interacting with her children due to the disability. Similar attitudes in neighbors and children were highlighted by LCUE1 and LCUE2. All the educated participants stressed the need for awareness among the general public regarding disability. According to MCE2 "... I feel that if opportunities are made for children in normal schools to mingle with children at special school on a particular day or occasionally, it will be useful for both children. Unique's sister knows about it since she is seeing him from childhood. But a person from a different background, will not be able to know what he

can do and what he cannot do. So, I think it will be an experience for children in both categories...”

Current status and future plans for a child with disability in Kerala

According to ten participants, their children with disabilities currently attend a special school. Two participants, UCE1 and UCE2 mentioned that their son has been staying home for the past five years as they were not satisfied with the training at the special school. Their son has a special interest in computers and car repairs, but the special school provides less opportunity for their son to explore that skill. UCLE1 and UCLE2 shared similar experiences about their 20 year old son who attends the special school where he is not receiving any vocational training that interests him. The parents could not find any other opportunities in their neighborhood, thus they continue to send him to the same special school. MCE1 is not satisfied with the training Unique receives for his age. MCE2 wants her child to learn vocational skills that relate to his interests. She said, “We don’t expect anything higher than a particular level in their studies. We want them to learn to read and write and understand things. We know that they will not become a scholar through learning. But it would be great if the school authorities can provide job training for them according to the interests and capabilities of these children.”

MCLE1 and MCLE2 shared their son’s inability to do basic living skills at home even at the age of 17. Saad has been attending special school for over ten years. LCE1 and LCE2 are satisfied with the services at the special school. According to them both of their children with disability have at least a place to go outside of the house from Monday through Friday. LCE2 thinks that “there is no point in keeping them at home and if so, someone should be there to look after them. Then, we will not be able to go for a job...I will send them there as long as possible.”

LCE2 agrees with LCE1's decision to send the twins to the school as long as they can. Both of them have the common belief that their twins with mental retardation can learn a job skill and become independent. LCUE1 and LCUE2 are happy of the fact that their son with mental retardation can perform all his living skills independently. Both of them would like to see their son learn a vocational skill. However, four of these participants do not see any opportunities in their community where their sons can learn and practice that skill.

When the question "What are your future plans?" was asked, all the mothers and two fathers of children with disabilities had their eyes filled with tears. They were unsure about the future of their child with disability after their demise. However, all of them have a hope that their son or daughter without disability will take care of their sibling with special needs. The participants in the upper class families have plans for arranging their sons' marriage to a person who can take care of them. They are not sure if they will be successful in their dream, being in a state like Kerala. LCUE1 and LCUE2 promise their son that they will help him to get married, in order to keep him in a good mood; but they said that it is a tool to manage his behavior and not a true promise. LCUE2 responds to the question of future plans by saying, "I am getting old...I am thinking. Every day I am thinking about what should be done with him. Will his disease be cured? Doctors are not saying anything clearly. If medicine is missed for one day, fits will come. I don't know how long the disability will be there. I am not able to do anything... we don't know what to do since we don't have any permanent means [source of income]... I sit alone and cry." UCE1, UCLE1, MCE1 shared their plan to have family properties registered to the names of their sons, who have a disability. They believe that such an action could be a reason for people to take care of their sons with special needs in the future. According to MCE1, he has spent money and educated his older son, thus expecting him to be the care provider of his younger brother

with disability upon the demise of MCE1 and MCE2. All the participants equally believe that the future of their child is in God's hands.

Cultural

The participants, despite differing socioeconomic status and possessing varying educational qualifications, shared common cultural practices, reflecting less diversity. During my visit to all the families, they served me a lot of food. This is a common cultural practice where guests or visitors are greeted by serving food. The researcher informed the participants prior to the interview neither to prepare any food nor spend money on anything during the visit. However in all the families, the researcher was offered tea along with more than four snacks. In both upper class and middle class families, the researcher was compelled to have dinner with the family after the snacks. When it came to the lower class families, four participants served home made snacks. In the lower class families, they served home made snacks to welcome the researcher. So the researcher was greeted in a similar manner across all participants. The themes that emerged around culture included: family values, belief system and understanding of disability versus disease.

Interdependent family values

All the participants in my study followed a life style where the father, mother and the children with and without disabilities lead an interdependent life. In other words, all the members were dependent on each other to perform most of their daily life activities. Except one parent MCE2, who worked part time, all female participants took care of the household while the male participants were the breadwinner in each family. MCE2 worked only part time, as she must take

care of the entire household, and her husband works in a different town, coming home only on weekends. LCUE1 mentioned that he does not have any job, but he considers it his job to bring in money to support the family. LCUE2 told about occasions when she had to borrow money from neighbors and family members, in order to make ends meet. All the participants have children with disabilities who are above the age of fifteen living at home with them. All of my participants see themselves taking care of their children with special needs for their entire lives. None of the participants in my study fully supported the idea that their son's education or older life should be in an institution or boarding school. The four participants of the lower class did share that such a solution was the only option in the absence of sufficient funds. However, LCE2 sees herself spending her time in that institution as a part time worker or volunteer with the hope that she can see her children with disabilities on a regular basis. The participants in my study find themselves to be care providers for their children for their entire lives and hope to pass on that responsibility to their other children without disabilities in their families. In other words, the societal structure around each participant's home offered very few opportunities to train their children with disabilities in developing a skill to be an independent and productive citizen. For example, UCE1 could not find any disability friendly computer centers or automobile workshops in three of his neighboring towns where his son could learn and develop computer or car repairing skills that would be compatible with his already revealed interests. The main reasons were lack of accessibility to centers located on second floors and absence of good toilet facilities. All the participants shared at some point during the interview their belief that their children with disability will not be able to make an income and contribute to the family. The upper class parents are ready to invest and help their children start their own businesses, or other ventures

that would help their son earn a living. However, they lack proper guidance and are also worried about sustainability.

When it came to the lifestyle within the home, the participants in the upper class family shared that their sons with disabilities have their own bedrooms. MCE1 and MCLE1 said that both their sons share a room with their siblings and once in a while sleep next to both parents. The four lower class participants said that two 16 and 19 year old sons were always sleeping next to parents. It is important to note that lower class families have houses with very limited space.

Belief System

India is a Hindu religious country. However, there are people who are Christians, Muslims, Sikhs, Parsis, Jain to name a few. The religious belief that is entrenched in the citizens presides over many important decisions and activities of daily living among the public throughout the different states in India. I would say that a child born in an Indian society receives lots of attention, care and celebrity from the members of family, community and from their respective religious groups. The feeding of a new born, naming of a child, onset of student life, getting a first job are some of the important events families celebrate with their son/daughter; often they perform many rituals as these milestones occur, in accordance with the family's culture and background.

All the participants in my study were strong believers of their respective religions. All of them maintained that their child's future is in God's hands. Except for one participant, UCE1, all my participants did not believe that the birth of their child with disability is due to their Karma or past deeds. Three of the male participants who are Muslims considered their family to be chosen

by their God to take care of their sons with special needs. MCE1 and MCE2 consider them to be strong believers of Hindu religion. According to MCE1 “I am a very deep believer. I talk to God everyday...his grace my younger daughter is a normal child...god will take care of my son...”. MCE2 told that her son attends the daily family pooja at home and also visit temple on a regular basis. LCE1 who is a Christian stated that his twins with mental retardation were given to him by God, thus he is unable to reject that gift. According to LCUE1 he tells everything to God, for example he says“...I’m a heart patient. I had a mild heart attack; doctors have told me to avoid drinking alcohol and smoking. My belief is that death can happen at any time, but it happens only when God calls for it. We also have to make some adjustments. Doctor once told me patting my shoulder that I’m great, God had saved me, otherwise I would have died...” So he thinks that his son’s day- to-day life is guided by God. LCE1 and LCE2, Catholic Christians, visit pilgrim centers and make offerings to their local church whenever their children are sick, refuse to attend school or have other behavior problems. While eleven out of twelve participants did not believe that past Karma or family deeds as reasons for their child’s disability, UCE1 strongly believed that it is his great grandfather’s actions that have resulted in the birth of his son with cerebral palsy. UCLE1 and UCLE2 shared how their son skips food for the whole day during the holy week of Ramadan, on a regular basis. According to the parents, they try to discourage Shawn from skipping food, but he refuses to take even a sip of water for the whole day during the whole holy month. When it comes to the belief system of LCE1 and LCE2, they train their children to perform daily family prayers at home.

Educational

There were less attitudinal differences across the six participants who possessed a higher education degree compared to their fellow participants living in the same socio economic status in the society. The educated participants in the upper class and middle class family were able to read and write English, thus able to interpret most of the writings by medical doctors on the prescription notes. This was not strength among the two participants who were less educated. The educated parents in the lower class family were trained in the native language thus English was foreign to both of them making it impossible to read English. The names of the disability identified in children of all participants were recorded in the school documents. However, neither the educated nor uneducated participants, except MCE1 and MCE2 supported those documented disabilities in their sons'. Similarly, ten participants regardless of their level of education and status expected a cure for the disability in their child. I am not sure if it is a cultural practice or the fear of being not accepted in society that forced the participants not want to talk about the exact disability in their children.

CHAPTER FIVE

DISCUSSION

In this research, I attempted to reveal and understand the social, cultural and educational attitudes faced by the parents of children with disabilities in the state of Kerala, India. This investigation identified several different attitudes towards disability that encumber the daily lives of parents and their children with disabilities. The study gave the opportunity for parents to talk about their journey with their sons who have disability, from birth to adulthood and about their plans for the future. The parents highlighted experiences from their day-to-day lives, as well as challenges within the family, the community and in society as a whole. The intention of this research is to help professionals and people in the field become more aware of the needs and rights of people with disabilities in India. As the participants were selected purposefully, parents of other children with disabilities in India can decide how closely these situations resemble their cases, thus supporting the transferability of the study, leading towards change in current practices. The findings of this study should stimulate future research.

While some of the findings reported here support earlier research, others are new. This study clearly reveals that the social, cultural and educational attitudes towards disability are intertwined, hindering the smooth functioning of people with disabilities in this society. The road to inclusion is filled with barriers that can be removed; however, such removal will be a slow process which needs support from all people living in the different strata of society. For full inclusion, a combined effort is needed by people from top to bottom.

In chapter four I discussed the data that emerged from the interviews according to specific themes. In this chapter, the highlighted themes, inductive in nature, are further cross-analyzed. The limitations of the study as well as implications for future practice and research will be discussed.

Limitations

This section includes an evaluation of the limitations of this study. These limitations include: demography and sample selection with lack of interview with parents of female children with disabilities.

The samples selected from the three towns have children with disabilities who receive services from the same special school. Four participants (MCE1, 2 and LCUE1, 2) have children who have attended other special schools, but they are currently receiving services from the same school where all other participants' children receive their education. Titi, son of UCE1 and 2 is not attending any school but was a former student of the same special school that all the other children currently attend. Hence, the participant's perception of special schools cannot be generalized to all other special schools in the state. Similarly there were no participants who were parents of female children with disabilities. So it will be hard to generalize the findings of this study to all children with disabilities and their families.

The researcher made an effort to find other participants who attend different special schools, but this particular special school caters to the needs of children with special needs in that region. Moreover, there were no female children who were in their adult age enrolled in this local special education program. Among the several other volunteers, this sample of twelve

participants is considered to be a very good purposeful sample that met the criteria for the study and that could contribute to the diversity and richness of the sample.

Summary of limitations and recommendations

Future research procedures could benefit by taking into consideration and addressing the several limitations and possible changes identified in this study. Increasing the sample size by including more participants from different parts of the state and within the country attending different special schools would serve the purpose of enhancing the results. Additionally spending more time with the family, periodic visits and staying in the community for longer periods of time before the actual interview could help participants to interact and talk freely with the researcher. Participants with children who have the same type of disabilities are another area to be considered when selecting the sample for future research. These considerations could provide deeper understanding of the lives of parents and their children with disabilities in the state of Kerala, India.

Implications

Medical Professionals

The current study reveals that there is a wide communication gap between the medical doctors and the parents of children with disabilities regarding the developmental delays or disability in children. It is unclear if the medical doctors communicated with parents about the disability in a professional language that was not understood, or if they hid the diagnosis from them, or if they failed to provide the correct diagnosis. Except for two, all participants highlighted the medical doctor's failure to identify the disability or communicate regarding any

developmental delays in their children at the time of or after the birth of their children. It took parents several consultations with new doctors to identify disabilities in their children. Twelve out of fourteen participants were neither knowledgeable about the exact type of disability in their sons nor understood the cause or reason for certain characteristics and behaviors in their adult children with special needs. Even though communication with the medical doctors was identified as a concern, it is important to note that the parents continued to seek their doctor's support in the absence of any other services. This study reveals that doctors influenced parents in major decision making processes. For example, families discussed that as a result of their doctors' advice, they had a second baby to support their son with special needs, sought education in a special school, and generally altered other future plans. It is clear from the study that the participants were hoping for a cure for their children's disability and continued to seek advice from various medical professionals. This hope for a cure and ongoing advice from medical doctors regarding children's lives dominated all participants' major decision making processes. Thus these results indicate that the families rely heavily on the medical model. The promises made by some medical doctors in a manner that generated hope to cure the disability in children was not only unprofessional but also led parents to experiment with new therapies and treatments for their children. The participants who spent over \$3,000 (US dollars) for treatment, or those who gave offerings and prayers to their respective gods could be actions that resulted from false advice given by professionals. The findings regarding misinformation and miscommunication from the medical field are new in the Indian literature. The domination of the lives of Indian citizens by the medical model has been previously reported (Alur, 2003; Kalyanpur, 2008; Singhal, 2005; 2006).

While a communication barrier has been identified between medical professionals and parents, there arises another cultural concern. The parents did not use the name or type of disability in their son throughout the interview; instead, they used terms like illness, walking problem, brain problem, nerve problem and low IQ as a name of the disability in their child. This tendency may be the result of a cultural inability to accept reality or that the parents really did not know the disability label. It is equally important to identify if the parents were aware that their child is less able and a cure is not possible. The parents who recognized the disability in their son (MCE1 and 2) spent most of their time in a foreign country, could be a reason for their more accurate recognition of the disability. This acceptance by two participants supports the possibility that parents can be educated about the disability in a culturally appropriate manner.

When one considers the history of special education in countries like the US, it is very clear that these current findings from India regarding the approach of medical doctors existed in the US prior to the enactment of the Education for All Handicap Children Act in 1975. It was only by eighteenth century that special education was accepted as a part of education in the US (Winzer, 2002).

Legal Knowledge

The findings regarding the lack of knowledge about laws and policies on special education among the parents of children with disabilities prevailed among all my participants, and this result has been documented by earlier studies (Kalyanpur & Gowramma, 2007). In the absence of support from the government or anyone outside of the family, parents are forced by societal pressure to care for their children with disabilities throughout their lives. This study supports Alur (2001) who stated that, “The

institution of family and its value system emerges as the strongest agency for care” (p.290). No doubt, the life of a child with disability without the support of family is bleak. The lack of support within the society reported by the participants is certainly their perspective, but it is equally important to consider interviewees who shared that corruption among government officials is a reason for the need to take care of the child at home. Issues like corruption, lack of knowledge among officers regarding allocation of funds locally, inaccurate data in government offices on disability, and no faith in promises by political leaders in power are other serious concerns. The unwillingness of officials from the top to bottom of the government to implement laws is a cause of confusion, as was clearly evident from the participant responses. Inefficient and disinterested leaders are in power at the top level. Despite the passage of several laws to implement inclusive education, an Indian 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). 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 who are to execute laws are in a state of confusion. This is very clear from the literature.

A dominant fear existed among the participants that their sons with disabilities might be “*oppressed*” by school officials if they sought admission in regular public school with the help of the court. This forced parents to be silent spectators of the injustices towards their children by the government officials. It is also evident that the

concept of demanding one's right was foreign to all my participants. They had little faith in the government, which, according to them, should be the source for change. Hence, the results of this study agree with Kalyanpur, who mentioned that the concept of demanding one's right is perceived as selfish or antisocial and is foreign to the majority of Indians (Kalyanpur, 2008). Based on the parent responses in the current study and looking at the current literature, when it comes to inclusive education, support or care from the government for people with disabilities is in its infancy. The above mentioned ten year old government report in 1994, if redone in 2009, would probably yield similar results. In other words, Indian parents must fill the vacuum caused by government's failure to care for or educate children with special needs.

Belief System

When it comes to the belief system in India, the results of this study contradict with previous studies that have shown that any disability in children is seen as the result of *karma* or past deeds (Alur, 2001; 2003; 2007, Mullatti, 1995; Timmons & Alur, 2004). In this study, 13 out of 14 participants did not agree with such a belief system. Instead, these families considered their sons to be a gift from god. There were participants who shared that their family was chosen by god to care for a son with special needs, which according to them is an action that all families cannot undertake. Another participant believed that he was able to succeed in business and reached a high status in society only after the birth of his son with special needs. In one word he stated "... my son brought good luck to our family..." However, all the participants did mention the strong belief among the general public that anyone with disability in a family is due to the result of their past deeds. This negative attitude among the general public and lack of awareness

about disabilities among typically developing children, adults and older people has built a wall of segregation within the whole society. This wall of myths and beliefs with no philosophical understanding has greatly influenced the minds of the public at large. I think that is another reason for government officials' inattentiveness to disability issues in the state, or in India as a whole. 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)

These types of societal and cultural attitudes pressure parents to be the care-givers for their children with disabilities for their entire lives. This cultural practice, without availability of any other option, further forces parents to believe that their children are not capable of learning skills that are mastered by typically developing children.

Summary of Implications for future practice

The participants in this study, parents of children with disabilities, have conveyed an important message that strong family support serves as the common ground for the every day life of children with special needs in all levels of society. The role of religion and its influence in the day today life of children with disabilities and their families is notable. Based on the findings and parental recommendations of this study, culturally appropriate practices can help build a strong inclusive community in this family-oriented society. The study implies the need for changes in the following areas :

Early Childhood

1. Hospitals to provide handouts on developmental milestones in young children to all parents after the birth of any new born.

2. Infant screening with the help of qualified professionals through out all hospitals.
3. Process for referring children and families to appropriate educational program
4. Educating medical doctors regarding an effective communication pattern with parents regarding developmental delays in children.
5. Educate doctors about the various disabilities
6. Leaders at local church or religious institutions to announce the importance of early intervention in young children and handouts on the various services to be made available to its members free of cost.
7. Education and training opportunities for general education teachers to learn about working with children with disabilities
8. Creating awareness about disabilities among all parents and people in the community
9. Local anganwadi's (pre schools)to open their school doors for children with disabilities, teachers to record progress in all children and communicating about delays, if any, with parents and provide support.

It is important to note that the participants discuss experiences about their children that started more than fifteen years ago. Since then, the government has passed several laws for inclusion and special services. There is lack of literature that discusses the effectiveness of those laws or their effectiveness. This opens the door for future research.

Elementary, Middle and High School years:

All the participants who took part in the study shared that their son's with disabilities were denied admission to local public schools. None of the parents questioned this injustice by local school officials because of their lack of knowledge on laws and their fear of their children being oppressed in school settings. The attitude by school officials and general educators towards the participants were not welcoming. These actions indicate the need for:

1. Educating parents on their children's right to a free appropriate inclusive education
2. Educating school officials and general educators on inclusive education
3. Educating typically developing children regarding the different types of disabilities and the need for including their peers with special needs.
4. Incorporating the concept of inclusion into the school curriculum .

Future

All the participants were unsure about their son's future. All of them shared the common understanding that their son will be a life-long dependent within their family. This vision of dependency that dominates the minds of all participants was possibly created by the socio cultural practices and poor leadership of government officials. The participants made it clear that they consider government's failure to ensure a quality life and education for their children with disabilities is due to the disinterest of political leaders. All of them strongly believe that government officials can bring about change and build strong inclusive communities. However, all of them are unsure if that will happen in the near future due to the following experiences: school officials denying admission for their son with disability, inability of local government officials to answer questions on disability related laws and rights, no response to the applications

submitted for government benefits and inability of officers to distribute disability related funds appropriately. These actions by officials are clear evidence that laws and policies for people with disabilities are not only being ignored but no one is held accountable for this human ignorance. To secure future and to avoid similar incidents for people in the coming generation, following recommendations could help address the current issues:

1. Open the doors of all local public schools for people with disabilities for a free appropriate education
2. Teachers and parents to identify vocational skills that interest each child with special needs, training them and finding placements locally.
3. Government officials work in local offices to be educated on disability issues, laws and policies at national and local level.
4. Government allocates funds to help families of adult children with disabilities learn vocational skills. The local government offices should execute this project, monitored by personnel who are knowledgeable about disability related issues.
5. Creating awareness among local businesses about disability and creating job opportunities within local community.
6. Monitoring the usage of funds that are allocated for specific disability related purposes with set dates for implementation
7. Immediate consequences for government officials who fail to complete task on time
8. Opportunity for parents to report their concerns to officials using a toll free number or via postal mails which will be confidential.

9. Local religious or community based groups to serve as supporting agencies that help the smooth transition of adults with disabilities to his or her local community.

Building strong inclusive community is a not an easy task, and it will take a lot of effort at the governmental level. In a populated country like India, where issues like poverty, child labor, HIV/ AIDS, homelessness, epidemic diseases and many other issues emerge on a daily basis, inclusive education is the only way to attain equality for people with disabilities. By admitting children with disabilities into local public schools, the parents save money for tuition, transportation and other school related expenses. This opportunity to learn from one another in local schools creates awareness about acceptance and equality among both children with and without disabilities, teachers, school officials and people in the local community. I believe that this learning environment can be created by mobilizing existing local resources, understanding local culture, uniting local manpower, supervised by knowledgeable leaders or parents of children with disabilities. These initiatives can lay a strong foundation for building a strong inclusive community. There is no doubt that inclusion will be a bridge that will help a person cross from childhood dependency into the harsher adult world, despite issues like inequality, injustices and segregation based on disability.

Implications for future Research

This study stimulates future research in several areas. First of all this same study can be conducted on a larger scale using a survey with similar questions throughout the state and in

other regions of the country. The themes that emerged through the interviews could be used for the development of the survey.

Secondly there exists several gaps in the literature where future research can be conducted. It includes:

1. Medical doctors communication pattern with parents and their influence on the daily life of families
2. Existing early intervention programs and services
3. Analyze the effectiveness of laws and policies that focus on serving children with disabilities and their implementation.
4. Corruption among government officials in the country for providing services related to disability.

Conclusion

Merging the Societal, Cultural and Educational Attitudes for Change

This investigation to understand the lives of children with disabilities through parents started only after an in-depth analysis of the literature. This study, focused on the social cultural and educational attitudes towards disability, is based on the personal experiences of parents of children with disabilities. As family practices across India are similar in nature, the findings of this study will help readers understand the daily lives of millions of children with disabilities and their families in India

It is important to acknowledge the reality that all the participants in my study live in a society that is in transition. Among the several other states, Kerala's development in the social

sector is commendable. However, when it comes to the education of children with disabilities, the people in all of the states follow the standard of living of the Indians prior to independence. Even though the British left India and the country gained freedom, children with disabilities and their families comprise a group that has a severely restricted freedom; they are free only within the four walls of their houses. If the government officials and people in Kerala feel proud about their achievements made in the social sector, they forget the reality that children with disabilities continue to be an oppressed minority. The parents who participated in my study have made it clear that their children's right to a free and appropriate education in regular schools remains a dream fifteen years after the passage of the Person with Disabilities Act of 1995. While officials and citizens of Kerala claim their state has eradicated the caste system and child labor, (these remain ongoing issues in the Northern part of India), I would say children with disabilities are still being treated as a minority similar to members of lower caste citizens.

Throughout this study, it is evident that the Indian family culture predominates over many other possible determiners of social practices. For instance, the educated and less educated participants advocated for common opportunities for achievement within the society. The participants faced similar problems irrespective of their education, wealth, or status. The rigid structures built by socio-cultural attitudes have segregated people with disabilities as a minority. Therefore to bring changes into the lives of children with disabilities, cultural values should remain the foundation for building any structures for inclusion of all people in this society.

The parents in this study have made it clear that laws and policies that have been enacted by the legislators are not implemented and thus remain window dressing; people with disabilities continue to rely on service of their family members without any support from the social welfare

programs of the state. The families in this study are prevented from participation in culturally appropriate inclusive education and the local school officials are equally unhelpful when they deny admission to children with disabilities for no proper ethical reasons. If these parents represent the other millions of parents of children with disabilities in India, then it is past time for parents to seek their rights using laws as their tools. People with disabilities in countries like the US have acknowledged that "... law has changed the nation's attitudes and made businesses and governments more willing to eliminate the hundreds of indignities they face every day"(David, 2000, p.5). Because of the implementation of the law in the US many Americans who thought the fate of children with disabilities was '*hopeless*' (Giardano, 2007, p.111) began instead to see their fate as hopeful. If implementing laws in the US has given life to the hopes and dreams of all people with disabilities and their families, it can yield similar results in countries like India as well. I support Alur, who stated that inclusion can happen in poorer countries. As she mentioned, there is no need to worry about deinstitutionalising or closing special schools. I strongly believe that existing special schools can be converted into vocational centers or places that offer after school programs for families. Such an initiative will help address the dreams of many people similar to my participants who would like to see their children master skills that are of their interests, contributing to the family. By opening doors to people with disabilities, millions of schools scattered around the country could promote equality and social justice, and give opportunity for those millions of children who have the same dreams and hopes as any other human being. It is past time for parents and children with disabilities to seek their rights from their local and national officials.

If inclusion has brought changes in western countries, similar changes can happen in countries like India. If Kerala has gained recognition at the national and international level for

the achievements in the social sector, no doubt the state can be a model place for implementing inclusion. Including all children will take time and require a joint effort by all people in the society.

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APPENDIX A

Appendix A includes the human subject consent form approved by the Washington State University Institutional Review Board, which satisfied all components of the human subject research project for this research study.

Appendix A

WASHINGTON STATE UNIVERSITY

(Department of Teaching and Learning)

Research Study Consent Form

Study Title: [How do social, cultural and educational attitudes towards disability affect families of children with disabilities and thereby affect the opportunities and daily experiences of children with disabilities in Kerala – India?]

Researchers:

Dr. Paulette E Mills, Ph.D. Chair (PI), Associate Professor of Special Education,

Washington State University, 509-335-5015, pmills@wsu.edu

Pavan John Antony (Co PI), Doctoral Candidate, Department of Teaching and Learning,
Washington State University, Pullman, 509-335-8832, pavanja@wsu.edu

You are being asked to take part in a research study carried out by Dr. Paulette Mills and Pavan John Antony. This form explains the research study and your part in it if you decide to join the study. Please read the form carefully, taking as much time as you need. Ask the researcher to explain anything you don't understand. You can decide not to join the study. If you join the study, you can change your mind later or quit at any time. There will be no penalty or loss of services or benefits if you decide to not take part in the study or quit later. This study has been approved for human subject participation by the Washington State University Institutional Review Board.

What is this study about?

The purpose of the study is to identify the social, cultural and educational attitudes towards disability and how it affect families and their children with disabilities in the state of Kerala – India.

You are being asked to take part because you are the parent of a child with disability.

Taking part in the study will take about one to two hours.

What will I be asked to do if I am in this study?

If you take part in the study, you will be asked to answer the following interview question: [See the attached questions)

Are there any benefits to me if I am in this study?

There is no direct benefit to you from being in this study.

This project will help parents of children with disabilities to inform the public in large about their daily life. As there is lack of literature from this state, by sharing personal experiences, the participants are letting the public know about their situation thus initiating the urge for change.

Are there any risks to me if I am in this study?

The potential risks from taking part in this study are not greater than minimal risk. There might be questions that are sensitive or emotional. You may decide not to answer a question or withdraw from the study at any point of time.

You may contact the local counseling center if needed.

Will my information be kept private?

All the data will be coded and none of your personal information will be revealed. This data will be kept in a locked cabinet and a key will be maintained separately. The interview transcriber will sign the confidentiality agreement before helping me with transcription. The transcriber will have access only to your voice and not to any of your personal information.

The digital or image recordings will be made and will be used for publications.

The data for this study will be kept confidential to the extent allowed by federal and state law. No published results will identify you, and your name will not be associated with the findings. Under certain circumstances, information that identifies you may be released for internal and external reviews of this project.

The results of this study may be published or presented at professional meetings, but the identities of all research participants will remain anonymous

The data for this study will be kept for three years .

Are there any costs or payments for being in this study?

There will be no costs to you for taking part in this study.

You will not receive money or any other form of compensation for taking part in this study.

Who can I talk to if I have questions?

If you have questions about this study or the information in this form, please contact the researcher **Mills, Paulette**, Assoc Prof, Teaching & Learning, Teaching and Learning, Cleveland 316, PO Box 642132, Pullman, WA 99164-2132, 509-335-5015, email: pmills@wsu.edu. If you have questions about your rights as a research participant, or would like to report a concern or complaint about this study, please contact the Washington State University Institutional Review Board at (509) 335-3668, or e-mail irb@wsu.edu, or regular mail at: Albrook 205, PO Box 643005, Pullman, WA 99164-3005.

What are my rights as a research study volunteer?

Your participation in this research study is completely voluntary. You may choose not to be a part of this study. There will be no penalty to you if you choose not to take part. You may choose not to answer specific questions or to stop participating at any time.

What does my signature on this consent form mean?

Your signature on this form means that:

- You understand the information given to you in this form
- You have been able to ask the researcher questions and state any concerns
- The researcher has responded to your questions and concerns
- You believe you understand the research study and the potential benefits and risks that are involved.

Statement of Consent

I give my voluntary consent to take part in this study. I will be given a copy of this consent document for my records.

The images of my child / family can be used for publications.

Signature of Participant

Date

Printed Name of Participant

Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect.

I certify that when this person signs this form, to the best of my knowledge, he or she understands the purpose, procedures, potential benefits, and potential risks of participation.

I also certify that he or she:

- Speaks the language used to explain this research
- Reads well enough to understand this form or, if not, this person is able to hear and understand when the form is read to him or her
- Does not have any problems that could make it hard to understand what it means to take part in this research.

Signature of Person Obtaining Consent

Date

Printed Name of Person Obtaining Consent

Role in the Research Study

APPENDIX B

Appendix B includes all the questions used for the interview, the major source of data collection for this research study.

Appendix B

Interview Questions

1. Tell me about your child and family.
 - a. Tell me about daily life for you and your child
 - b. As the parent of a child with disability, tell me about your experiences within the home and in the community,
 - c. Discuss the relationship between your child with disability and his or her siblings
 - d. Relationship between other family members and relatives.
 - e. Tell me about your belief system (religion's role in your everyday life)

2. What are the different services you receive for your child with disability?
 - a. Tell me about the services you receive for your child
(from the government, NGO's, the Community and other agencies)
 - b. How did you find out about these services?
 - c. Are these services provided free of cost?
 - d. Do you receive any governmental support?
 - e. How useful are these services?
 - f. Tell me about the quality of these various services
 - g. Do you think this is the best service for your child?

3. How familiar are you with your child's individual rights and laws?
 - a. Laws and policies
 - b. Inclusive education?

(if they do not talk about inclusion in answer to my above questions)

 - c. Where does your child currently receive education or any other services?
 - d. Have you sought admission for your child to the local public school? If not, why?
 - e. Have you ever been denied education in public or private special schools? Why?
 - f. How do you feel about your child being integrated into the regular education classroom?
 - g. What could government do to implement inclusion?

4. Tell me about a typical day when you are at a public place with your child with disability.
 - a. How do you get to places with your child with disability?
 - b. How often you all go out with your child with disability (public events, shopping, social gatherings)
 - c. Do you rely on public or private transportation?
 - d. What are the major challenges you have in during these days?
 - e. What else?

5. What are the current strengths and weaknesses in the system regarding the services for people with disabilities?

6. What are your future plans and expectations for your child?
7. How do you feel about a system which would include and educate all children?
8. Do you as a parent think the system should change? If so, what can contribute to a change in the current system?