

Education in Special Schools: A Forced Choice and A Privilege. Case Studies from South India

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Abstract

As of today there are few researchers who have examined the lives of parents and their children with disabilities who live in the state of Kerala a state in the South West India. A qualitative case study methodology is adopted to understand the daily life experiences of families and their children with disabilities, who reside in upper, middle and lower class of the Indian society. This article attempts to help scholars, parents and professionals around the world better understand: (1) the current special education system and (2) the daily life experiences of families and their children with disabilities in South India. The findings highlight that parents and children with disabilities face challenges at different levels from the time of birth through adulthood. The case studies are employed to explain why the lead researcher claims that receiving any special education or related services for children with disabilities in Kerala, India, can be a privilege and also a forced choice without any other options. Recommendations for including all children in local public schools and implications for practice are presented.

Keywords: children with disabilities, Indian education, family, inclusion, special schools

Introduction and Background

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, most of whom practice them on a daily basis. 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. There are some people who believe that a child is a "...fruit given by god" (Mullatti, 1995, p.9), while others consider children to be '*innocent beings*' in the society (Srinivasan & Karlan (1997)). Therefore, a child born in an Indian society receives much attention, care, and recognition 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 ostracization of a child with disabilities and his or her family by the people and the community at large begins from the time of birth. Children with disabilities at large are denied admission to local public schools and are forced to identify resources by their own. 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 knowledge about the cause of disability among 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 children's disability will be cured one day. Timmons & Alur (2004) have discussed how neighbours 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.

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). 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 in India. 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). In other words, many children with disabilities are denied their basic right to receive a Free Appropriate Education in an inclusive classroom. During a recent visit (2016) to four special schools in different parts of Kerala, India, the researcher learned that children with mild and some moderate disabilities are at times initially admitted to Anganwadis (preschools in Kerala). However, these students are forced to leave school if they exhibit any behaviours like screaming, running around, slow learning or not paying attention. The researcher also met a student with learning disability in one of the special schools who was forced out of school as she was not able to perform like her peers without disabilities. The student currently attends a special school with children with intellectual disability, autism, Cerebral Palsy and multiple disabilities. One of the school officials in the special schools attested that it was a common practice. This is happening while there is a law to implement inclusive education in India. The special education laws, policies, present, past and future are already documented in the literature (Antony, 2013; Sharma & Das 2015). These failures of the government either to implement laws, sustain initiatives, or upscale them to a national level has already been critiqued (Antony, 2013; Singhal, 2006). Antony (2013) has already discussed the confusion from top level government officials to the people at lower levels regarding the inclusive system of education. He has also argued that the confusion has permitted special schools to increase in number, thus taking away precious resources in the country, without solving the issue. The lack of understanding about inclusion, its goals, processes and motivation underpinning such efforts are still not understood by the Indian government (Singhal, 2006). The flourishing of special schools all over India in the presence of a law to implement inclusion questions the government's interest in implementing inclusive education in the nation. The failure at the government level to implement laws has already been critiqued (Antony, 2012; Kalyanpur, 2008; Sharma and Das, 2015; Singhal, 2006). The lack of commitment by the Government of India to implement inclusive system of education and ongoing challenges at different levels is already recored (Sharma and Das, 2015).

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.

Research Design

Purpose of the study

To my knowledge, limited research has been carried out in the state of 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 are not inclusive. 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. Thus, I decided to study the special education system, the daily life experiences of children with disabilities and their parents living in the Indian society. I also wanted to understand why there has been little forward movement in the effort to improve the lives of persons with disabilities in Kerala.

Methods

A qualitative case study methodology was adopted to understand the families and their children with disabilities. This type of research helps readers to 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 have chosen 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. This methodology has helped me to examine personal reactions and 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 limited research, my study can help fuel the development of future large scale studies. This research methodology has 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 from which to gather data regarding the day- to-day life experiences of their children.

Critical theory was adopted 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.

Data Collection

Interviews were the primary sources for data collection. Participants were selected with the help of a non-profit organization and 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 travelled 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 interview consisted of previously developed open ended questions that reflected the research objectives. 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 the translation of 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.

Participants

A total of eight participants (four families) took part in the study. Out of a total of four families, two families were selected from below the poverty line category and two families from the upper class of the Indian society. The socioeconomic classifications of these families were based on governmental records and set criteria. Four participants, one couple from each classification, possessed a higher degree of education than fellow participants who were less educated in their respective group. To protect the identity of all participants, real names have been replaced with a new name. The participants who were educated and belong to the upper class are identified as Mr. John Mathew and Mrs. Pearl Mathew (Bachelor's degree) and those people who were less educated (high school) are identified as Mr. Salam Hussain and Mrs. Sali Hussain. Similarly, the educated people in the lower class are identified as Mr. Abin Thomas and Mrs. Nina Thomas (tenth grade) and the less educated (below 5th grade) as Mr. Shah Arafat and Mrs. Najeem Arafat. Please refer to Table 1 for participant details.

Mr. and Mrs. Mathew live in a small town two miles away from the city in a modern two storied house. Both of them are former college graduates. Mr. Mathew runs a business in the nearby city and Mrs. Mathew takes care of the household. They have two children: an older girl is finishing up her Bachelor's degree in Computer Science and the younger boy (Titi), who has Cerebral Palsy, stays at home. Mr. and Mrs. Mathew consider themselves as strong followers of Jesus Christ and shared their identity as Orthodox Christians. They own two private vehicles; one car was mainly used for their sons' travel. They do not rely on public transportation for their travel.

Mr. and Mrs. Hussain live in another small town in a newly built two storied building ten miles away from the city. Mr. Hussain runs businesses in the neighbouring state and Mrs. Hussain takes care of children at home. They have three chil-

dren; the older girl is married and stays with her husband in a neighbouring 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. Mr. and Mrs. Hussain shared that all of their family members are Muslims. They have a private vehicle and do not depend on public transportation.

Mr. and Mrs. Thomas live in a small house with two rooms, away from the big city. Mr. Thomas is a painter and Mrs. Thomas takes care of the household. Mrs. Thomas also works part time as a helper at a nursery school in their neighbourhood. Both of them have completed tenth grade. They live in a colony, 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 many houses that are built close to one another. A small fence made out of plants serves as a boundary between their house and the neighbours. There were several small posters of Jesus, the Virgin Mary and various saints up on the wall in their small living room. The family have a small nice home with two rooms and a kitchen. Mr. and Mrs. Thomas consider their living room to be their daily prayer room and dining room. They are proud that they live in a Christian neighbourhood. They are fully dependent on public transportation and avoid most travel plans due to their children's disability. They have three children; the two older boys (Alaas and Vilaas) are twins who have intellectual disability and the younger boy attends the local public school. The twins attend a special school 20 miles away from home. Mr. and Mrs. Thomas are followers of Jesus Christ and shared that they are Roman Catholics. They do not have any private vehicle and are dependent on public transportation.

Mr. and Mrs. Arafat also live in a colony, away from the city. 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 parents are unemployed. They identify themselves as Muslims. There were two rooms in the house and a kitchen. Their house is not plastered and Mr. Arafat shares that they do not even have money for their daily living. There were several paper cuttings of mosque and proverbs pasted on their walls. According to Mr. and Mrs. Arafat, 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.

Data Analysis

The method of analysis was in my own data (Charmaz, 2005; 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 re-examined and analysed. Member checking was adopted throughout the study. 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 or edit the information if needed. These data along with the reflective journals were used for data analysis.

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
Mr. Mathew Mrs. Mathew	Bachelors Bachelors	Upper Class	Christian	Cerebral Palsy	Nil Walking problem	Titi - 20, male	1 older girl
Mr. Hussain Mrs. Hussain	10 th grade 10 th grade	Upper Class	Muslim	Cerebral Palsy	nerve problem brain problem	Shawn - 20, male	1 older girl & 1 younger girl
Mr. Thomas Mrs. Thomas	10 th grade 10 th grade	Lower Class	Christian	Mental Retardation (twins)	Sick children	Alaas and Vilaas, 16, male	1 younger boy
Mr. Arafat Mrs. Arafat	Below 5 th grade	Lower Class	Muslim	Mental Retardation	Brain problem / sickness	Dahas – male, 19	1 younger girl

Table 1: Participant Details

Findings

Several common themes emerged from the data regarding the socio-cultural educational attitudes towards disability. There were more commonalities than differences among children with disabilities and their families who belong to different socio economic class of the Indian society.

Misleading advice from medical doctors

The medical doctors influenced all the parents in the major decision making process regarding the lives of their children with disabilities. All the 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 children's symptoms. All participants came to know about the disability in their child when they noticed developmental delays, leading to consultation with new doctors. Mr. and Mrs. Thomas interpreted the disability in their son to be a disease, Mr. and Mrs. Arafat interpreted it as a disease, while Mr. Mathew, Mr. and Mrs. Hussain named the disability a nerve or brain problem and Mrs. Mathew shared it as a walking problem.

The children in the upper class families were born in private hospitals while the children in lower class families were born in their local government hospitals. Mr. and Mrs. Mathew shared that their newborn cried continuously after birth. According to Mr. Mathew, after the birth of Titi (who has Cerebral Palsy), 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 Mr. or Mrs. Mathew regarding any developmental delays in their newborn. After 24 days of returning home, they took Titi to a pediatrician in another hospital. This time the new doctor labelled him as "... a case of retardation." The doctor told Mr. Mathew that the brain of the child was damaged due to the fits and this was the reason Baby Titi cried continuously.

Shawn who has Cerebral Palsy, s/o Mr. and Mrs. Hussain was also born in a private hospital in a bigger city in the neighbouring town. Mrs. Hussain had a normal delivery and they left for home the same week. The doctors did not communicate regarding any developmental delays in their newborn. Mrs. Hussain noticed that her sister's son who was born on the same day as Shawn had many skills that she did not notice in her son. Mr. and Mrs. Hussain noticed that their son was not able to lift up his head, roll over onto his back or side or make any sounds like Mrs. Hussain's sister's child. By the fourth month, Mr. Hussain took an appointment with another doctor in the neighbouring state where he ran businesses. The doctor told him that their son had some nerve weaknesses. According to Mr. Hussain 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..." Mr. Hussain believes that it is the fault of the doctors and states "...they hide it from us". According to Mr. Hussain 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 Mrs. Hussain, the doctors informed her about a cyst in her stomach and the chances of having some complications during the delivery of Shawn. Mrs. Hussain 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 Mrs. Hussain shared these new developments and her belief about the delay in her son with the previous doctor and hospital officials who supervised Shawn's delivery, they denied the same saying "... nothing similar is recorded..." Mr. Hussain 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.

Mr. and Mrs. Thomas have twins with intellectual disabilities. Alaas and Vilaas were born in the nearby public hospital. It was only by the eighth month of pregnancy that Mr. and Mrs. Thomas realized that they were going to have twin babies. According to Mr. Thomas, doctors shared that one of the babies could not be rescued and so the father would have to sign some papers. Mr. Thomas signed the papers but was not aware of their contents. However, his wife gave birth to the twins and had no complications. According to Mr. Thomas a yellow colour 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 Mrs. Thomas 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 Mr. and Mrs. Thomas about their children's disability. When Mr. and Mrs. Thomas noticed delays in their children even at the age of eight, they consulted a new doctor at a new hospital. Mr. Thomas 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.

Dahas, s/o Mr. and Mrs. Arafat has intellectual disability. He was born at a nearby public hospital, which is 3 miles away from home. The delivery was normal and Mrs. Arafat 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 Mr. and Mrs. Arafat that 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 Mr. Arafat that "...the brain development is happening slowly in Dahas due to the fits in his early years and hence medicine should be given continuously throughout his life..." Mr. and Mrs. Arafat believe that their son has a disease that can be cured. However, Mr. Arafat shared what the doctors told him "... this disease cannot be cured by giving medicines". Today when his son is 19, Mr. Arafat thinks that 80% of his son's misbehaviour at home is due to his disease and 20 % is due to laziness. At the time of this interview, he believes that his son's brain has stopped developing.

Mr. and Mrs. Hussain were told by a new doctor that the disability in their baby was due to the doctor's carelessness at the time of their child's birth. This communication style not only upset the parents but

left them in a situation with less hope. All the parents in the lower socio economic status shared that being poor was one of the main reasons that they did not

question the medical professionals. Mr. Thomas said, "... we are poor...what can we do? ...god will help us..." Mr. Hussain believes that, the failure of the doctors to communicate effectively is "...a big fault or mistake..." All the participants in the study shared that they were advised by their doctors to take their children to special schools for education. One of the doctor told Mr. and Mrs. Thomas that their children "...cannot be educated with normal children in regular schools..." In other words, all the parents in this study decided to provide special education for their children based on their doctor's advice. In India states like Kerala, especially special schools are the only places where children with disabilities could receive an education. Based on my recent visit in 2011, there are few private schools for typically developing children that admits children with disabilities but there is lack of literature to support this statement.

Treatment for Cure

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 lower class families admitted their inability to spend money for multiple treatments. However, they continue to spend money for religious rituals and other home based treatments to cure the disability in their children. The participants in the upper class family experimented with treatments like allopathic medicines, Ayurveda (herbal treatment), massage, Yoga, and homeopathy. They took their children with disabilities for several treatments; they are still willing to spend money if their children can be cured. In the case of Mr. and Mrs. Mathew, their family doctor advised to "... spend money for the child expecting no return..." Mrs. Mathew defines her son's disability as a walking problem while Mr. Mathew did not make any comments to define the disability in his son. Mr. Hussain defined the disability in his son as a nerve problem and Mrs. Hussain stated it as a brain problem. The parents admitted that they spent money on their sons' treatments expecting a cure. Mr. and Mrs. Mathew started treatment for fits in Titi on the 29th day after his birth, gave medicine for three years and did not notice fits after that. Mr. and Mrs. Mathew 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. Mr. Mathew 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 without a disability..."

All the relatives and grandparents of Shawn expected a cure for his disability. Mr. and Mrs. Hussain 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. Mr. and Mrs. Hussain 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 centre that offered this massage to Shawn promised Mr. and Mrs. Hussain that the therapy would cure the Cerebral Palsy 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 therapy centre by him-

self 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 centre. However, Mrs. Hussain 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 centre used lot of force for stretching different body parts, and that the procedure was painful. During the day of the interview, while Mrs. Hussain 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...".

Mr. and Mrs. Thomas defined the disability in their children as "sickness". The participants often mentioned that their children were "...Sughamillatha Kuttikal..." which means "...children who are not well...". Throughout the time of interview, both Mr. and Mrs. Thomas classified their children as sick. They shared that much money was spent on a regular basis for their children's medicines. According to them these medicines along with their regular prayers will hopefully cure the disability in their children sometime in the future. Lastly, Mr. and Mrs Arafat shared that their child is sick and his brain is slightly affected. They shared mixed feelings regarding a cure for their son's disability. Mr. Arafat stated that "... Allah could cure my son's disability but don't know when..." and Mrs. Arafat believes that her son's disability will be cured sometime in the future. During the interview process, they classified the disability in their son as '*sicknesses*'.

Disability: God's Blessing or karma

All the participants in my study were strong believers of their respective religions. All of them irrespective of their education or socioeconomic status, maintained that their children's future are in God's hands. Except for one participant, Mr. Mathew, all my participants did not believe that the birth of their child with disability is due to their Karma or past deeds. The participants shared that it is the general public who do not have children with any disabilities that hold such a belief system. 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. While seven out of eight participants did not believe that past Karma or family deeds as reasons for their children's disabilities, Mr. Mathew strongly believed that it is his great grandfather's actions that have resulted in the birth of his son with cerebral palsy. Mr. Mathew 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 grandfather, 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. Mr. Mathew further shared that for the past several years, he has been donating money as offerings to the Hindu god as repentance for his great grandfathers' action. When it comes to the belief system of all the participants, they train their children to perform daily family prayers at home.

All the participants in this study identified themselves as deep believers of their respective religion. Mr. and Mrs. Mathew 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. Both parents shared that they go to church regularly and consider their daily family prayers in front of the framed picture of Jesus Christ a family routine.

Mr. and Mrs. Hussain are strong followers of the Muslim religion. According to both parents, they practice their religion and offer prayer on a regular basis. Mr. and Mrs. Hussain 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. Mrs. Hussain shares an incident where Shawn refused to take a sip of water after a severe seizure at the special school. Shawn responded to the teachers who offered water "... Allah will take care of me..." According to Mr. Hussain, Shawn participates actively in all the religious festivals. Both parents do not believe that their son's birth is due to any karma or past deeds.

Mr. and Mrs. Thomas shared that they are strong believers in Jesus 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 centre that is 100 miles away from home. Mr. Thomas sees the birth of his children with disabilities as a gift of God and thus he is "...unable to reject the gift..." Mr. and Mrs. Thomas who are catholic Christians, visit pilgrim centres and make offerings to their local church whenever their children are sick, refuse to attend school or have other behaviour problems. Mr. Thomas 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.

Mr. Arafat 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 several paper cuttings of the mosque that were pasted to the wall at the entrance of the house. Both Mr. and Mrs. Arafat are strong believers in the Muslim religion. Mr Arafat offers prayers at Mosque on a daily basis, while Mrs. Arafat 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. Mrs. Arafat shared that her son offers prayer on a daily basis during the holy month. Both parents do not believe that their son's disability, or in this case the disease, is due to the past deeds or karma. Mr. Arafat compares his son's disability with other students attending special school and thinks his son is far better. He believes the disease in his son is a 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... Allah takes care of my son on a daily basis... there are times that I thought of killing myself and my son... but I won't do it as Allah said NO..."

According to Mr. Arafat, 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.

Legal Knowledge and individual rights

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 was aware of their children'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. 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.

All the participants were unaware of their children's right to a free appropriate public education or about the current legal system in special education. School officials told Mrs. Mathew "... Titi is not able to walk, there is a chance for other children to knock him down..." and denied admission. The school principal told Mrs. Hussain, "... your son cannot even sit with good posture... how come he can attend regular classes?" Mrs. Hussain was very upset about the school official's reply and decided to take Shawn to a special school. Public school officials denied Shawn admission to three local public schools because of his inability to walk Mrs. Hussain states "... if I was knowledgeable about the legal system, I would have taken this issue to the court for justice... but I do not know the law or school system". Mr. Hussain believes in change, but does not think it will come soon through the government.

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." Mrs. Arafat believes that no one can identify the disability in his son by just looking at him, "... he looks like a normal child". So the school officials might have admitted him unknowingly. Both parents were upset by the response from the school officials.

Alaas and Vilaas were also denied admission to the local public schools. The school officials denied admission stating "... your children have communication problems". Mr. and Mrs. Thomas shared that they did know how to respond to the school official's reply. Thomas states, "... we are poor and do not know about the rights... this gives a greater power for school officials to deny any child their educational rights based on a disability".

Twenty-year-old Shawn and his parents are still unaware of disability rights for an Indian citizen. According to Mrs. Hussain, Shawn was denied financial help for free appropriate education 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. To Mr. and Mrs. Hussain's knowledge, the majority of services for people with disabilities in the state are catered through private non-profit organizations and not through the government. Ac-

ording to Mr. Hussain, God has created individuals who have passion to serve people with disabilities, and they are the ones who run these organizations. Both parents of Shawn were unaware of the laws and policies on inclusive education.

Mr. and Mrs. Thomas 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, Mr Thomas 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."

Mr. Thomas thinks that his children will behave appropriately with typically developing children. Both parents shared their fear about the treatment of their children by their typically developing peers. 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. 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. Mrs. Thomas asked me, "Will there ever be a legal system that will solve the problem of parents likes us?"

Based on the advice from medical doctors, Mr. and Mrs. Arafat admitted 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. They shared their wish about learning about their rights when their son was young. They also shared that being poor, they cannot advocate for their rights.

Uncertainty of the future

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 children 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' marriages to a people who can take care of them. They are not sure if they will be successful in their dream, being in a state like Kerala. Mrs. Hussain is unsure about the practicality of such a dream in the current Kerala society. Mr. Mathew is ready to spend money to arrange a bride for his son through an arranged marriage. However, he is not sure if anyone will be willing to marry his son with a disability. Mr. Hussain 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, Mr. Hussain is worried if strangers or other relatives "... may intend to kill him and take the income. So, we cannot trust anyone. We cannot trust relatives and our own people in this matter". 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. Mr. Hussain 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...” Mr. and Mrs Hussain are not sure if Shawn’s sisters will take care of him as they will be married off to another family. Mr. Hussain 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.

Mr. and Mrs. Mathew strongly believe that parents and siblings are the ultimate care providers for anyone with a disability in Indian society. According to Mrs. Mathew, 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. Mr. and Mrs. Mathew do not consider Titi a problem, but Mrs. Mathew shared that Titi feels uncomfortable being in public, outside the home setting. Both Mr. and Mrs. Mathew are unsure about Titi’s future. Mr. Mathew has registered some family property in the name of Titi to secure his future. Mr. Mathew believes that his older daughter will take care of Titi, while Mrs. Mathew 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.

Mr. and Mrs. Arafat 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 behaviour and not a true promise. Mrs Arafat shares about her husband drinking alcohol on a daily basis and about days when her husband threatens to kill her son by giving him rat poison. Further, Mrs. Arafat shared that

“... neighbours 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...neighbours at my mother’s 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...”.

Mrs. Arafat shared these few experiences and bursts into tears. She is afraid of how people will treat her son in future. Mrs Arafat 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.”

All of the participants envision 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 in the lower class did share that boarding school will be a solution if they did not have sufficient funds in future. However, Mrs. Thomas sees herself spending her time in that boarding school or 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.

Discussion Summary

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 and influence of medical doctors, values and belief system, legal knowledge and the future of a child with disability in the state of Kerala.

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. One of the major findings highlights that 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 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 a 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, thus making it impossible for them to read English. The names of the disability identified in the children of all participants were recorded in the school documents. However, neither the educated, less educated nor uneducated participants supported those documented disabilities in their sons. Similarly, all 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 to want to talk about the exact disability in their children.

It is very important to note that states like Kerala in South west India are societies in transition. However, the case studies reveal that parents and their children with disabilities face segregation from the society at large right from the time of birth. The parents whether educated, less educated or uneducated have lost faith in the government and continue to remain illiterate regarding their legal rights. All the parents believed that it is due to the lack of government support that children with disabilities face segregation thorough out their lives. Mathew's son has been staying at 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. Mr. and Mrs. Hussain 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. All the parents shared that they could not find any opportunities other than special schools run by non-profit organisations in their local communities to help children with disabilities. Thus special schools continue to be the only option for children and adults with disabilities. The stories of these parents are powerful testimonies encouraging the need for an inclusive system of education.

Limitations of study

The limitations include: demography and small 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. Titi, son of Mr. and Mrs. Mathew 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 eight 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.

Implications for 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 everyday life of children with special needs in all levels of society. The role of religion and its influence in the day-to-day 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 :

- Hospitals to provide handouts on developmental milestones in young children to all parents after the birth of any new born in their native language.
- Educating medical doctors regarding an effective communication pattern with parents regarding developmental delays in children.
- Educate doctors about the various disabilities.
- Infant screening with the help of qualified professionals through out all hospitals.
- Process for referring children and families to appropriate educational program.
- 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.
- 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.

- Education and training opportunities for general education teachers to learn about working with children with disabilities.
- Creating awareness about disabilities among all parents and people in the community.
- Educating parents on their children's right to a free appropriate inclusive education.
- Educating school officials and general educators on inclusive education.
- Educating typically developing children regarding the different types of disabilities and the need for engaging with their peers with special needs.
- Incorporating the concept of inclusion into the school curriculum.
- Open the doors of all local public schools for people with disabilities for a free appropriate education.
- Teachers and parents to identify vocational skills that interest each child with special needs, training them and finding placements locally.
- 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.
- Monitoring the usage of funds that are allocated for specific disability related purposes with set dates for implementation.
- Immediate consequences for government officials who fail to complete task on time.
- Opportunity for parents to report their concerns to officials using a toll free number or via postal mails which will be confidential.
- Creating awareness among local businesses about disability and creating job opportunities within local community.
- 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.

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:

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

Conclusion

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. It is identified that receiving any special education or related services for children with disabilities in inclusive settings in public schools, remain a dream for millions of children in the country. The continued denial of students with disabilities to receive any education in public schools and forcing them to drop public schooling by school officials continues to be a reality. There is lack of literature that highlights the struggle parents face as a result of these kinds of injustices. It is evident that special schooling is a privilege for few, a dream for many and also a forced choice with no other options in the society. The stories in this study inform the family practices at different levels that is happening in the society. 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. The public schools have initiated admitting children with disabilities to few public schools, but most schools do not admit students with moderate or severe disabilities. There is lack of literature that has identified the current status of inclusion in public schools in Kerala. It is important to comment and recognise Kerala's development in the social sector compared to several other states in the nation. However, when it comes to the education of children with disabilities, the people in most 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 shared 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 labour, (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.

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 coun-

tries 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 to educate children with disabilities in public schools in the US many Americans who thought the fate of children with disabilities were 'hopeless' (Giardano, 2007, p.111), began instead to see their fate as hopeful. If implementing laws in the West 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 centres 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. 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. Inclusive education remains the one and only solution to eliminate segregation and achieve Education for All in countries like India. It is past time for parents and children with disabilities to seek their rights from their local and national officials.

Conclusion

Including all children will take time and require a joint effort by all people in the society. 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. By admitting all children to the local public schools, the state can produce revolutionary results, helping children with and without disabilities to learn, grow and build stronger communities together.

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