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A New Face in the Crowd: An Examination on the Social Integration of Children With Disabilities

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A NEW FACE IN THE CROWD:
AN EXAMINATION ON THE SOCIAL
INTEGRATION OF CHILDREN WITH
DISABILITIES

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Fall 2011

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Abstract

Historically in India people with disabilities have been pushed to the side and have not been given the attention which they need and deserve. As a result this population has become extremely marginalized and has not been included in making decisions with the rest of society. The main reason why this has become such a marginalized group is because of a negative stigma which has been associated with mental disabilities. Slowly this stigma is beginning to change, but it still affects the way people view and act towards the disabled. The integration of people with disabilities into the rest of society is important for further development in India. This study examines what is helping and what is preventing the social integration of children with disabilities in India. The study took place in Varanasi, Uttar Pradesh and the Sirmour district of Himachal Pradesh. In each of these locations an NGO was worked with to obtain data through the use interviews and personal observations. This study found that stigma is what is holding people with disabilities back from being able to socially integrate with the rest of society.

Introduction

India straddles two worlds at the same time and finds a balance being both a developed and developing nation. In these two worlds there people who each have a different set of abilities, skills, struggles, and talents. In recent years, India has made progress towards becoming a developed country, but before India can actually be considered a developed country there are many sections of society which need to be improved. People with disabilities in India have been marginalized and their voices have been overlooked. Giving rights to people with disabilities and integrating the disabled into everyday society are just two things India needs to do to continue to move towards development. Change is needed from the everyday attitudes society has towards the disabled to proper implementation of national policy. India cannot continue to develop without addressing the needs of all the members of the nation.

Presently, people with disabilities are one of the most marginalized groups in Indian society. The disabled have not been given the same opportunities as the rest of society, and as a result they have fallen behind in many areas (Subramanyan & Sekhar, 2010). The

majority of people with disabilities have been disabled since birth or before they were old enough to go to school (Thomas, 2005). Because of this most people with disabilities are poorly educated and are way behind where they should be in the current times. People with disabilities are not being given services to help them catch up with the rest of society, instead they are mainly being ignored and not integrated into society. Understanding why people with disabilities are not being integrated into society is important because it can lead to changing what is causing them to be excluded and integrate people with disabilities.

This study explores how children with disabilities are being socially excluded in Indian society. A few questions this study aims to answer are is there still a negative stigma surrounding disabilities and what role does this play in social inclusion of children with disabilities, how do families aid in social inclusion or exclusion of their disabled children, and what are institutions doing to help disabled children become more integrated into society? The goal of this paper to provide further understanding on what is helping and preventing children with disabilities from being socially included in society. The findings of this study conclude that stigma, family, and institutions are the main sources of progressing and preventing children with disabilities from being integrated into society.

Research for this study was accomplished through the help and aid of KIRAN and the Social Institute of Deliberate Human Immanence, SIDHI. These two organizations each work with disabled children; each organization has their own goals and uses their own methods to provide help for both children with disabilities and their families. These two organizations were used for this study because through both information can be collected from a disabled community, families of disabled children, an urban setting, and a rural

setting. The locations of KIRAN and SIDHI provided views from people with a variety with different backgrounds.

Information for this study was collected through the use of participatory observation and formal and informal interviews with staff, volunteers, and family members of disabled children. Previous literature has been used in support of the information ascertained in these areas. Literature specific to the region was difficult to acquire because not much research has been done on this topic in these two places, but many previous studies can be generalized to these areas.

Defining Disability and Disability Estimates in India

Disability is difficult to define and definitions vary from one person to person and organization to organization. One reason disability is so difficult for people to define is because disabilities vary in type, form, and intensity (Chaudhuri, 2006). According to the World Health Organization “disability is any restriction or lack (resulting from an impairment) of ability to perform in a manner or within the range considered normal for a human being.” (Chandhuri, 2006). In India, under the Persons with Disabilities Act of 1995 disability is defined as one or more of the following categories: blindness, low visions, leprosy cured, hearing impairment, locomotor disability, mental retardation, and mental illness. In order for one of these categories to be considered a disability the person must not suffer from less than forty percent of any one disability (Thomas, 2005). The National Sample Survey Office considers disability as “any restriction or lack of abilities to perform an activity in the manner or within the range considered normal for human being.” This definition does not encompass illness or injury of recent origin resulting in temporary loss of ability to see, hear, speak, or more (Chaudhuri, 2006). As can be seen from these three

definitions there is no one universal understanding of disabilities. For the use of this paper disability is defined as “a person who in his/her own society is regarded as disabled, because of a difference in appearances and/ or behavior” (Chaudhuri, 2006). This is a simple definition and encompasses the concept of no universal definition of disability.

The most recent census in India took place in 2001. This census reported that 2.2% of the total Indian population has a disability. This number has been largely disputed by organizations working in the disability field. These organizations contest that approximately six percent of the Indian population is disabled (Thomas, 2005). The census also found that the majority of the disabled population can be found residing in the rural areas of India. Although these figures may not be precise they are able to provide an overview of the disabled population and provide the understanding that people with disabilities are a large part of the Indian society. How can such a large population of people be so marginalized in society? India is making strides to emerge as a developed nation, but how is it possible for a country be developed when such a large group of people are being neglected and pushed to the side? People with disabilities in India are extremely marginalized and not integrated into the rest of society.

Social Exclusion of the Disabled

Social exclusion revolves around social identities of people or groups and reflects the cultural devaluation of people based on their identities (Subramanyan & Sekhar, 2010). People with disabilities are very socially excluded in the current Indian society. People with disabilities are left out of development planning and their voices are not heard in decision making circles. The attitudes people have towards those with disabilities, compounded with

institutional and environmental barriers, results in the discrimination and exclusion of this group of people (Subramanyan & Sekhar, 2010).

People with disabilities have significantly lower education and employment rates from the rest of the country, and this gap has been increasing over the past fifteen years (Subramanyan & Sekhar, 2010). Most people with disabilities are capable of doing productive work, but most employers do not realize this and are not willing to hire people with disabilities. People with certain types of disabilities, such as hearing, speech, and locomotor disabilities, are more likely to get a job over someone with mental illness. Recently, there has been a decline in the employment rate of people with disabilities. The employment of people with disabilities went from 42.7 percent in 1991 to 37.6 percent in 2002 (Subramanyan & Sekhar, 2010). This trend shows that the exclusion of people with disabilities is a growing problem in India.

One model which aims at explaining the exclusion of people with disabilities is the social model. This model sees disability as the social consequences of having impairment (Subramanyan & Sekhar, 2010). The inequalities faced by people with disabilities can only be overcome if society is willing to become inclusive. The social model accepts that people with disabilities have impairments which affect how they function both physically and mentally, but it also states that these people are more disabled by the barriers that exist in society (Subramanyan & Sekhar, 2010). These barriers are in the physical, organizational, and personal aspects of society. Some examples of these barriers are stairs without ramps or lifts, information not available in Braille, or the negative attitudes of people. People with disabilities should enjoy the same freedom and choices as enjoyed by the non-disabled and be allowed equal responsibility in determining their life choices (Subramanyan & Sekhar,

2010). Based on this model it is easy to see that society is what is holding back people with disabilities from being integrated and in order for them to be integrated it is society which needs to change.

Government Policy and Initiatives

In order to understand the current situation for the disabled in India it is important to review the current rights of the disabled based on legislation. Understanding the current legislation is critical to understanding the current status and integration of the disabled because it is through legislation which people with disabilities are given their rights. Legislation provides insight into what the government says they will do to help and how the government is working to give rights to people with disabilities in society.

Overall, India has one of the more developed national policy frameworks for disability in developing countries (Human Development Unit, 2010). However, in many places in the country this policy is not being properly implemented. India does not have a long history of acknowledging the existence of disabilities and as a result there has not been a lot of legislation stating the rights of people with disabilities. It was not until the 1980s that policy commitment to full participation of people with disabilities in Indian society evolved. There have been a few key pieces of legislation which give rights to people with disabilities: the Mental Health Act, 1987; the Persons with Disabilities (Equal Opportunities, Protection of Rights, and Full Participation) Act, 1995; the Rehabilitation Council of India Act, 1992 and amended in 2000; and the National trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation, and Multiple Disabilities Act, 1999 (Human Development Unit, 2007).

Out of all these legislations it is the People with Disabilities act of 1995 which been the cornerstone helping the disabled. The main provisions of this act are education, employment, prevention and early detection of disabilities, affirmative action, and non-discrimination in access. This has taken the rights of the disabled past a medical stance and has included social rights of the disabled (Human Development Unit, 2007). There are four major sections in this act which aim at the social rights of the disabled.

The first main section is education. In the education part of the act the government has ensured that children with disabilities have access to free education in an appropriate environment until the age of eighteen. The government will ensure teacher training that produces the requisite manpower for teaching children with disabilities both in special and integrated settings. All public institutions shall reserve not less than three percent of the seats in a classroom for people with disabilities. Finally, the government should prepare a comprehensive education scheme for children with disabilities which include transport or financial incentives, barrier free access, supply of book, uniforms and learning materials to children with disabilities (Human Development Unit, 2007).

The next section of the act is employment for people with disabilities. The act states that the government will identify posts for people with disabilities in public establishments and update that list every three years. At least three percent of posts in public sectors must be reserved, and one percent needs to be reserved for those with blindness, hearing impairment, locomotor disability, or cerebral palsy. Through this a small percent of the population with disability should be able to find employment in the public work field. In order to help people with disabilities find employment the government and local authorities will formulate schemes for promotion of employment of people with disabilities. To

promote their employment the government will provide training for people with disabilities in certain areas of work. This helps people with disabilities find employment by providing them with skills necessary to work in certain areas.

The next major section of the act is prevention and early detection of disabilities. This part of the act is extremely important because the earlier a disability is identified the more can be done to help the child progress faster in life. In this section the government says they will undertake surveys on the causes of disabilities, promote various methods for identifying disabilities, screen children at least once a year for identifying at risk causes, provide facilities for training staff, and sponsor campaigns on hygiene, health, sanitation, and causes of disabilities (Human Development Unit, 2007). All the provisions under this section of the document are “within the limits of the government’s economic capacity and development” (Human Development Unit, 2007).

Affirmative action and non-discrimination in access are the last two major sections of the act. In the affirmative action section of the act the government will frame schemes for the provision of aids and appliances to people with disabilities and allot land for housing, business, recreation centers, special schools, research centers, and factories run by entrepreneurs for people with disabilities. The final section of the act is non-discrimination in access. This section states that the government will adapt all forms of transportation to make them accessible to people with disabilities and provide for a variety of assistive devices in the built environment. These devices include auditory signals, ramps in public, buildings and health facilities, Braille signage, accessible curbing, marked crossings, and warning signals as appropriate (Human Development Unit, 2007). Currently, the cities in

India are inaccessible for people with disabilities and this aims at providing devices which will make the cities more accessible.

What is stated in the People with Disabilities Act of 1995 sounds great and according to the act people with disabilities should be fully integrated into society, but this is not the case. The Act is not being properly implemented and this is keeping people with disabilities from being integrated with the rest of society. This key piece of legislation for people with disabilities is not working as it says it will and those with disabilities are not being given their rights (Human Development Unit, 2007).

Background Information on KIRAN

KIRAN works as a center for education, training, and rehabilitation of children with different abilities. One of the main beliefs guiding KIRAN's mission is that every child has the right to life, to care, to education, and to later on work. This is what their services revolve around. KIRAN works with children with a variety of disabilities including cerebral palsy, hearing impairment, vision impairment, mental retardation, autism, and multiple disability. The main goal of KIRAN's services is to help integrate disabled children easier into everyday society and provide them with the rights they are given under the Persons with Disabilities Act of 1995.

The mission of KIRAN is to support the parents of differently-able children through quality services, so that their child will be empowered as much as possible in a holistic way for an all around healthy life as an adult. Also, to share the know-how experience with persons and organizations who wish to do the same kind of service. KIRAN uses this mission statement as the center of all the services they provide for the children and family.

KIRAN fulfills this mission through a focus on individual care of the children in physical rehabilitation, education, skill-trainings, and enhancement of artistic abilities. At the center KIRAN provides children and families with fourteen different services. One of the main services KIRAN provides is a primary school and NOIS. Here formal education is provided to children with and without disabilities from kindergarten to fifth standard. Through this inclusive classroom setting the children are able to learn socialization skills necessary to integrate into a regular school setting. In the classroom the students follow the normal academic curriculum of academics as designed by the Uttar Pradesh government. Once a child completes fifth standard the goal is to be integrated into regular schools in their community, but those with a disability too severe to be integrated into normal classrooms can continue their studies at KIRAN up to 12th class.

For the children who have a disability which is too severe to be in the KIRAN classroom, special education is provided. Special education is mainly provided to children who have cerebral palsy and hearing impairment because these disabilities are hard to have in the regular classroom. There are four different sections in the special education service: functional academic group, self help group, academic groups, and life skills group. Each one of these groups focuses on a different area and the children are placed into the groups depending on their disability and its severity.

Another service KIRAN provides is social integration and vocational training. These two departments work together towards the ultimate goal of empowerment for the children. Social integration works with children who have already completed their studies at KIRAN. Here they are integrated into other schools or are provided with vocational training, throughout the whole process both the disabled child and family receive support from the

staff. In the vocational training department there are five different areas of study: wood workshop IQ toys, horticulture, bakery, tailoring, and art and design. These trainings empower the children and improve their self-confidence to become more independent while earning their own living and lead their lives with dignity and self determination. One option which helps these children to reach this goal is for them to receive a loan from KIRAN, so they can start their own small business. This service allows the children to feel more freedom as they take responsibility for their own finances.

The disabled in India are often not given their rights under the People with Disabilities Act of 1995, so KIRAN is working towards giving the disabled the rights they deserve. Through KIRAN many children have been given skills which will help them live a more independent life and feel empowered that they are able to do things on their own. This is the goal of KIRAN and what the services they provide revolves around.

Background Information on SIDHI

SIDHI is an NGO working in the Sirmour district of Himachal Pradesh to provide disabled children with home based education. SIDHI is based in the town of Dadahu and covers a 65 kilometer radius from this point. This area is mainly a rural area and most of the people living in the area have slight economic problems. SIDHI was started in 1999 as a non-profit working towards the improvement of the poor and deprived communities in this area. This organization was started as a grass roots organization and still continues to work from the grass roots level. All of the staff of this organization are from the local area and have been properly trained to work in their areas. Since 1999 SIDHI has developed their programs and during the process began working with disabled children in the area.

The mission of SIDHI is to work with people to end poverty and illiteracy in the area. SIDHI also works to help people acquire the skills to be knowledgeable, confident, and resourceful in leading local actions. This change is attempted by helping people become aware of their rights and give them the skills to ensure they are given those rights. SIDHI works with many people in the nearby villages and one population of people they work with are disabled children and their families.

In this area SIDHI is the only organization providing and services for disabled children. Because there are no special schools anywhere near, most of the children have not received a proper education. Access to services in this area is very difficult. Sirmour is located in the lower Himalayas and the terrain in this area makes it difficult to get around. Most of the disabled children were diagnosed when they were young, but have not seen a doctor regularly since that visit. The fact that most children do not regularly go to the doctors means that it is likely that there are many other children living in the area who haven't been diagnosed by a doctor and not are receiving the services they are given rights to. SIDHI works to locate these children and families and to begin providing them with services which will benefit the child.

Currently, SIDHI is working with twenty-one children in the area. When they first began they worked with forty children, but due to a lack of funds they were forced to cut back in the number of children whom they provide services to. SIDHI works with a wide range of disabilities, those including hearing impairment, visual impairment, cerebral palsy, mental retardation, and multiple disabilities. For the kids they work with this is the only sort of education which they are being provided or have access to. Each child works one on one with a trained special educator. The program of the child is individualized to meet the

child's disability and level of disability. For fifteen days every month a special educator goes to the home of the child to work on the designed educational program. At the end of every visit the special educator notes down exactly what was done with the child.

Stigmas and Attitudes Surrounding Disabilities

In India people have had negative attitudes towards the disabled. These attitudes come from a time in which people did not have a very good understanding about disabilities. At the time, people turned to religion searching for an explanation behind disabilities (Kar, 2008). Religion was something the people believed they understood, and so it made sense to use religion as an explanation for why someone is disabled. Religion also plays a very large role in the lives of many people living in India and religion is often used as a source of explanation for an unknown event (Kar, 2008). A few of the explanations used by people include spirit possession, witch craft, breaking of religious taboos, divine retribution, and the capture of the soul spirit (Kar, 2008). These beliefs marginalized and excluded people with disabilities from the rest of society.

Still today religion plays a role in the way people explain disabilities and this then affects their attitude towards the disabled. A common belief about disabilities today is that disabilities are a bad thing from a past life carrying over (Mr. Amil Kumar Shaya, personal interview, November 11,2011). People often think that they did a bad thing in their past life and now they have to make up for it with this everyday problem of having a disabled child (Mr. Amil Kumar Shaya, personal interview, November 11,2011). Out of twelve interviews seven parents used this to explain why their child was born with or acquired a disability. Institutions also said many parents whom they worked with use their past life as an explanation for having a disabled child in their current life (Mr. Amil Kumar Shaya,

personal interview, November 11,2011). Using religion to explain disabilities can create both positive and negative attitudes towards people with disabilities.

It is common for families to feel that it is their duty to take good care of their disabled child. For those who think disabled children are a result of something they did wrong in their past life, they believe they take it upon themselves now to make up for that time in their past life (Mr. Sanjeev Awasthi, personal interview, November 19, 2011). In these situations the family has a positive attitude towards the child and do not let previous stigmas influence their thinking. When people think like this it is also common for them to describe disabled children as “a gift from God.” Out of the seven interviews which used this explanation, five of the interviewees used this phrase. When religion is used to have a positive attitude towards disabilities the disabled children tend to be more socially included in events with family and friends.

The Thakur family is a good example of a family in which religion is used to have a positive attitude towards their disabled child. Prashant Thakur is a nine year old boy living in the town of Dadahu in Himachal Pradesh. Prashant is nine years old and has been diagnosed with cerebral palsy and mental retardation. When Prashant was four years old his parents realized that he was not developing as a normal child should. It was at this time which he was diagnosed. Currently Prashant is non-vocal and can only stand with support. His parents both agree that he can be a lot to take care of at times, but they see him as God’s gift and their duty (Mrs. Vimla Thakur, personal interview, Parent, November 15, 2011). They have accepted his presence in their life and consider him very important. At times they do feel helpless when dealing with Prashant because there is only so much they can do for him, but this feeling quickly fades and they remember that he is their duty (Mr. Vijay

Thakur, personal interview, November 15, 2011). The Thakur family uses religion to focus on their child and make sure he receives everything they can provide for him. When they begin to feel negative about the situation they remember Prashant is their duty and do the best they can for him. Because this family is accepting of Prashant he is not hidden in the house, but is included in societal events the family attends.

None of the families interviewed for this study used religion to create a negative explanation and attitude towards having a disabled child. Now it is less common for people to use religion in a negative way, but according to staff working at KIRAN parents sometimes do see their disabled child as a curse (Mrs. Surita Gautam, personal interview, November 9, 2011). Children who are thought of as a curse are rarely taken out of the home and do not interact with people outside the family. Even within the family many of the family members are not likely to spend a lot of their time interacting with the child (Mrs. Surita Gautam, personal interview, November 9, 2011). The attitude associated with disabilities does play a large role in how often disabled children are brought out of their home and into the rest of society.

The thing that plays the largest role in how people think about disabilities is their education level. Those with a higher education level have an easier time understanding and accepting disabilities. As a result of this acceptance they also have a positive attitude towards the disabled. They do not use religion as an explanation and have more of an understanding on what causes disabilities (Mrs. Jaya Sushin, personal interview, November 11, 2011). Those who are educated are not embarrassed to have a disabled child and whenever possible take their disabled child out of the home (Mrs. Surita Gautam, personal

interview, November 9, 2011). Educated families put a large focus on the integration of their child into everyday society.

In Varanasi there were many more parents who had received an education than parents living in the Sirmour district. As a result it is generally easier for the KIRAN staff to have parents understand disabilities than for the SIDHI staff. According to the 2001 census, sixty percent of people in villages are literate, compared to eighty percent of people living in cities. In the cities eighty-six percent of males and seventy-two percent of females are literate. In rural areas seventy percent of men and forty-seven percent of women are literate (Planet Read, November 11, 2011).

Based on these figures it makes sense that KIRAN is going to have more educated parents than SIDHI. Out of the twelve families which were interviewed in the Sirmour district the highest level of education reached by any of the parents was tenth standard, but the majority of parents had only gone to school until fifth standard and twenty-five percent of the parents were illiterate. The exact numbers for education is unknown for parents working with KIRAN, but at least fifty percent of the parents were literate and attended school up until tenth standard (Mrs. Jaya Sushin, personal interview, November 11, 2011). Because the parents living in the Varanasi area had higher education rates they also had an easier time accepting their child's disability and spent more time taking their child out of the home and socializing with other people (Mr. Amil Kumar Shaya, personal interview, November 11, 2011).

Another factor which helps decrease negative attitudes towards people with disabilities is exposure to the disabled (Mr. Amil Kumar Shaya, personal interview, November 11, 2011). In the past, people with disabilities have been hidden away in the

back of homes, but as people with disabilities are coming out into the public people are beginning to have a better understanding (Subramanyan & Sekhar, 2010). This exposure causes people to see that the stigma which has been associated with disabilities no longer applies. In many situations people judge based on what they hear, but once they experience it for themselves that previous belief is dropped (Mr. Amil Kumar Shaya, personal interview, November 11, 2011).

Family connections are the main way in which most people are learning about disabilities, and these connections are adding to the decrease in negative attitudes towards those with disabilities. When one family has a disabled child and they are open about the child, then friends of the family are going to be accepting and curious to learn more (Mr. Amil Kumar Shaya, personal interview, November 11, 2011). Through parents being accepting of their own child the public is also going to experience an attitude shift and be more accepting. People living in cities are going to have an easier time understanding the reasons behind disability, but this does not necessarily mean those living in rural areas are not going to be as accepting. There are not many institutions working for people with disabilities in rural areas, so the main way in which people in these areas learn about disabilities is through knowing someone who has a disability.

In rural areas, more so than in urban areas, there are still a large number of people who do not know anything about disabilities and think about disabilities with a negative stigma (Mr. Sanjeev Awasthi, personal interview, November 19, 2011). In the Sirmour district there are no special schools for people with disabilities and SIDHI is the only organization working with disabled children in the area, so exposure to the disabled is the main way in which people in this area are learning about disabilities. Before having a

disabled child, none of the twelve parents who were interviewed had known anything about disabilities. The birth of their own disabled child brought around their exposure and at this point they had to learn about their own child's disability. When people are not educated on disabilities they are more likely going to continue to have a negative attitude towards those with disabilities. This negative attitude then prevents children with disabilities from being socially included in society.

In a village near Varanasi a fourteen year old girl was in an accident which took away her ability to walk. After this accident her entire village did not think she would be able to do anything else with her life. Even the girl began to think she was not capable of doing anything and developed a negative perspective on her own life. One year after the accident KIRAN found this girl and brought her to the KIRAN center for rehabilitation. She lived at the center for a little over a year and underwent a very comprehensive rehabilitation. At the end of her time at KIRAN she was able to walk with the help of assistive devices. Throughout this year it was possible to begin to see a change in her personality. As she was making progress in her rehabilitation she began to regain the confidence that she lost as a result of losing her ability to walk. When she returned to her village all of the people were so impressed and happy to see the improvement she had made. No one in the village thought she would be ever be able to walk or do anything independently (Mr. Raghubeer Singh, personal interview, November 13, 2011). Situations like this are the reason negative stigma is beginning to fade through exposure. Once people begin to understand that those with disabilities are capable of living a near to "normal" life they begin to have a better understanding and a more positive attitude towards the disabled.

Role of Family in Social Integration

Families play an extremely important role in the social inclusion of children with disabilities. The family is responsible for making most of the decisions for the child, so the decisions they make are going to impact the social inclusion of the child. The caretaker is the one who is responsible for providing emotional support, case management, financial assistance, advocacy, and housing (Dixon, McFarlane, Lefley, Luckstead, Cohen, Falloon, Mueser, Miklowitz, Solomon, & Sondheimer, 2001). The majority of the time the caretaker to children with disabilities is the parents, but it is not too uncommon for a child to be taken care of by a grandparent or other relative (Lyons, Leon, Phelps, & Dunleavy, 2009). These family members are the main source determining a child's level of social inclusion.

When thinking about planning a family most people do not imagine one of their children will be disabled (Stanley & Lalitha, 2009). So when parents find out their child is disabled it is initially hard news for the family to hear. Families' reactions and adjustments to having a disabled child are going to vary from case to case. It is impossible to predict just how one family is going to react, but there are a few factors which can impact a family's adjustment to having a disabled child. One factor in a family's reaction is the type of disability and the severity of the disability (Stanley & Lalitha, 2009). When a child completely relies on his or her family for support and cannot do many things independently, the family is going to have a harder adjustment than if the disability still allows the child to do some things independently. Children who have severe cerebral palsy and mental retardation are going to require a lot more time from the family than a child who has a hearing impairment. But both children still need dedication from the parents in order to learn and do things independently, but there are just more physical things a child with a

hearing impairment will be able to do independently (Mr. Amil Kumar Shaya, personal interview, November 11, 2011). The families' reaction to having a disabled child is going to greatly impact the amount of social inclusion the child experiences.

Out of the twelve families who were interviewed in the Sirmour district four of the children had disabilities which did not have a physical affect. Two of the children had hearing impairments, one had a visual impairment, and one was autistic. Based on observation these children were much more integrated into their communities than the children with physical impairments. These children did have better means of accessing their communities because they are able to mainly get around on their own, but the families of these children were also more accepting of the disability. In interviews the parents of these four children said having a child with disabilities has had very little impact on their daily schedule and life. Of families of the eight other children who were interviewed, five of the families said having a disabled child has had an impact on their daily routine. The amount that a child can do independently is going to affect how socially included they are in the society.

In a village outside of Dadahu lives Chaman Ram. Chaman is sixteen years old and suffers from a hearing impairment. Two years ago Chaman began working with the organization SIDHI. Up until that point Chaman had no proper education, but was able to do many things around the house on his own. Chaman and his family had no formal training on sign language, but amongst themselves they created their own sign language to communicate with each other. Chaman never had the opportunity to go to school because of his hearing impairment, but he is still able to function very independently. He works on the family farm with his parents and needs hardly any assistance around the house (Mrs. Vimla

Devi, personal interview, November 22, 2011). Chaman's independence has made it so there is very little social exclusion from his family and community. The only way in which Chaman is socially excluded is through exclusion from schools. Chaman is a good example of a child who is disabled, but still is included in all the same activities of his family and community. He is given the opportunity to be included in all of the social events (Mr. Rayia Ram, personal interview, November 22, 2011).

Another factor affecting the social inclusion of children with disabilities is parents' and families' views on disabilities. These views are going to revolve around the parents' and families' conception of normality, services available for people with disabilities in the area, reputation of the family, parents aspirations for the child, and the extent to which parents are involved in making decisions (Pandey, 2004). Families who have a more open mind about what they consider to be "normal" are going to have an easier accepting a disabled child, who is seen by some as "not normal" (Pandey, 2004). There are a lot of factors influencing just how a family is going to react, but the overall idea is that families who have a positive attitude about having a disabled child are going to have an easier adjustment and be more willing to spend time working with the child.

This is especially important in home based educational programs. In the SIDHI program special educators and physical therapists only go to the home for a short period of time and can only work with the child for so long before they have to leave. SIDHI has special educators going to the home of disabled children for fifteen days a month, for the rest of the month it is up to parents to work with the child. When parents do not work with the child, he or she progresses at a much slower rate than if the parent works with the child everyday (Mr. Sanjeev Awasthi, personal interview, November 19, 2011). In the Sirmour

district it has been found that when parents dedicate time and spend time working with the child they have the ability to progress to a level which they could not imagine in the beginning.

One example of a child who has shown huge improvements because of the work of the parents is Dinesh Kumar. Dinesh is ten years old and at the age of three was diagnosed with cerebral palsy and mental retardation. For five years he has been working with SIDHI and throughout these five years his skills have improved immensely. When he first began working with SIDHI he was unable to stand or walk. He spent a majority of his time lying on his back on a mat in the front of his home (Mr. Sunder Singh, personal interview, November 22, 2011). Before working with SIDHI Dinesh's parents and family did not have knowledge on what they could do to help him. At first when the family was working with SIDHI they did not think he would be able to improve very much, but after three or four months they were very impressed by the skills he had developed (Mr. Sunder Singh, personal interview, November 22, 2011).

Now, after five years Dinesh is able to stand and walk on his own. The main reason Dinesh has made such a huge improvement is because of the help of his mother, Tara Devi (Mr. Sanjeev Awasthi, personal interview, November 19, 2011). Tara Devi took the time to provide the physical therapy she had been taught by the physical therapists and devoted time everyday to the improvement of her son. Another reason Dinesh has been able to come so far is because he began receiving physical therapy when he was still pretty young. The younger the children are when they begin physical therapy and education the chances of improvement are better (Mrs. Jaya Sushiri, personal interview, November 11, 2011). Dinesh is one success story in which the parents were optimistic about his success and committed a

lot of time to his improvement. Through Dinesh's improvements he has become more integrated into his society. Dinesh is now able to attend social events more easily and his parents enjoy taking him to events to show friends and family just how much progress he has made (Mr. Sanjeev Awasthi, personal interview, November 19, 2011).

Unlike Dinesh's story some parents are not as eager to commit time and energy to spend working and socializing with their disabled child. Pakija Ram is a six year old girl with limb impairment and cerebral palsy. For the past four years Pakija has been working with SIDHI. Over these past four years she has barely made any progress in her development. Pakija lives in a joint family home, but her family does not spend time with her or take her out of the house very often (Mr. Sanjeev Awasthi, personal interview, November 23, 2011). Pakija's mother is the only one who spends any sort of time with her, but even her mother does not dedicate as much time as is needed. Pakija's mother makes sure that she is given the necessities, but she does not work on Pakija's education or physical therapy. As a result, Pakija has not made much progress over the past four years. The main reason the family does not spend time working with Pakija is because they do not think she will ever make much progress. What the family does not realize is that if time was spent working with Pakija she would make progress (Mr. Sanjeev Awasthi, personal interview, November 23, 2011).

As can be seen from Pakija's situation when families neglect a child because of his/her disability, that child is never going to make progress towards doing things independently. Pakija also shows that a family's belief really does impact how they treat their child. In Pakija's circumstance her family does not think she will ever be able to make much progress in doing things on her own, so they do not spend time with her. Her parents

do not have a thorough understanding of disabilities and this is impacting the rest of Pakija's life.

The way in which Pakija's parents view disabilities also impacts the social inclusion of Pakija. Pakija gets hardly any social interaction with people outside her family. This is a result of her parents thinking she will not be able to do anything with the rest of her life. When parents do not think optimistically about their child's disability, they do not put energy into the integration of their child with the rest of society (Pandey, 2004). There is only a small fraction of parents who do not think their child will amount to anything, but for the children of these parents it has a great impact on the rest of their lives.

It is not uncommon for parents to think for the first few months of working with an organization that their child will not make any progress. Of the twelve families interviewed in Sirmour ten of the families were not expecting their child to improve in the beginning. It was not until two or three months of working with SIDHI that they began to see the potential of their child. Of the families interviewed in the Sirmour district, Pakija's family was the only who felt that there was no hope. Pakija's parents lacked understanding about her disability and as a result had a negative attitude about the disability.

Because parents have ultimate authority over the child it is important that they have a clear understanding of their child's disability and the needs of the child. This is one reason why organizations put such a large emphasis on counseling and educating parents of children with disabilities (Mrs. Surita Gautam, personal interview, November 9, 2011). Through counseling, parents learn about the disability of their child and what is going to be most beneficial for the child. Most families do not have previous knowledge on disabilities and need to be taught about their child's disability in order for the child to receive proper

care (Mr. Sanjeev Awasthi, personal interview, November 19, 2011). Through this education most parents begin to develop a positive attitude towards their disabled child because they begin to have more of an understanding about their child's disability. Further counseling is also provided to families who need more help understanding and accepting their child's disability (Mr. Sanjeev Awasthi, personal interview, November 19, 2011).

Role of institutions in Social Integration

The role of institutions in the social integration of children with disabilities is to guide parents and to provide disabled children with a group of people in which they can interact. As discussed before, institutions have a major role to play within families. Institutions do a lot for changing negative mentalities families have towards their child with disabilities and as a result help in the social integration of the child. Institutions are also important in providing a setting for children with disabilities to interact with one another as well as with children who do not have disabilities. By providing a setting where children can socialize with each other the kids learn skills which are important to have when socializing with other people. This then provides children with disabilities the skills required to be socially integrated into the rest of society.

There are a variety of ways in which institutions can provide services for children with disabilities to interact with other people and improve their social skills so at some point the children can be integrated into the larger society. The systems used by KIRAN and SIDHI to socialize children are very different, and given the two different environments it is necessary for the two institutions to have different methods. Both organizations have adapted their programs to work for their environment. Because KIRAN is located near to

Varanasi, a more urban setting, the socialization here is going to be different from SIDHI which is located in a rural area of the lower Himalayas.

KIRAN provides a very social atmosphere for children with disabilities. The main service which provides most of the socialization for children is the integrated school. Here disabled and non-disabled children are able to interact and learn from each other. This classroom setting is very beneficial for disabled children because they are able to learn good socialization skills and habits of the non-disabled children (Lakhan, 2009). Often disabled children will pick up undesirable habits such as thumb sucking, spitting, body rocking, crying, defiance, throwing objects, repeating words, and stammering (Lakhan, 2009). Being in a classroom with non-disabled students will discourage these types of actions from the children with disabilities. By gaining social skills accepted at KIRAN the children with disabilities are also learning social skills accepted by the larger area and will then have the skills to be integrated into the society.

Based on personal observation, all of the inclusive classrooms at KIRAN were very orderly and the majority of the students were behaving themselves. In these classrooms the disabled children were not acting out or showing any habits which would not be desirable in most situations. This is one of the main goals of having inclusive education, providing disabled children with the opportunity to observe how other kids act in the same setting. From appearance at KIRAN this seemed to be working and the disabled children had learned how to act because of the kids around them. This statement cannot be generalized for all of the children because their behaviors and actions are dependent upon disability and its severity (Subramanyan & Sekhar, 2010). Children with cerebral palsy or mental retardation are going to have a more difficult time being aware of their own actions and

noticing the actions of the other children. It is going to take longer for these kids to understand ways in which they should and should not be behaving.

Another section of the KIRAN school is the hearing impairment classes. These classes consist of ten to twelve children who all have hearing impairments. From observation of this classroom things were not going as smoothly compared to the integrated class. It was not uncommon to see one of the children smack another upside the head or mock a peer across the room. In this setting the children were learning bad behaviors and continued to use these behaviors and copy each other. All of these actions took place whilst the teacher was either not in the room or had her back turned from the class. The bad behaviors of one child are being replicated by the other in the classroom. Bullying and picking on each other are not good social skills for these children to learn, but at the same time this is not going to have a very detrimental impact on the children's social integration.

KIRAN's ultimate goal is to help socially integrate disabled children into the everyday life of society, so all of their services revolve around children with disabilities learning what they need to know in order to function more smoothly in society (Mr. Amil Kumar Shaya, personal interview, November 11, 2011). From observations at the center ,KIRAN's system has been working very well on the socialization of the kids. The majority of the kids at the center are not shy to talk with new people and are very eager to find out more information about any new visitors. The children with whom I had the opportunity to interact with all politely introduced themselves and knew how to hold a conversation. Before starting at KIRAN children have very little social skills and at this time would not be well integrated into society.

In the parent and child care unit observations were recorded on how children behave and act before entering one of the KIRAN programs. The children who have not yet begun working with KIRAN are much more dependent on their parents and are not very good at socializing with others. Up until this point most of these children have not been in a situation where they have been forced to do things on their own, and as a result they are highly dependent on their parents. These children have also not had a lot of experience interacting with people outside their family, so they have not yet acquired the social skills needed to get around in society. One example of this is Amit. Amit is twenty four years old and has not had the opportunity to socialize with very many other children. He is very introverted and does not like spending time around other people. KIRAN was working with Amit to teach him how to interact with other people, so that he can be join one of the vocational training departments. Many children who first begin working with KIRAN are extremely introverted like Amit.

Once children have been working with KIRAN for a few months they begin to become less introverted and more willing to interact with others (Mrs. Jaya Sushin, personal interview, November 11, 2011). After being at KIRAN most of the children begin to learn how to interact appropriately with other people and they also gain more independence because for a period of time everyday they are not with their parents. By being without their parents the children learn how to be on their own and this is an important skill for them to have in order to be socially integrated into society. If children want to be integrated they cannot be completely dependent on their parents, but have to be able to do some things on their own.

In vocational skill training the socialization skills which the young adults learned after spending at least one year at KIRAN are easy to see. One way in which the effects of socialization can be seen is through the confidence coming from those in the programs. The young adults in this area are mostly between the ages of sixteen and twenty, many of them had been students in the KIRAN school before joining vocational training. The social skills of these young adults truly show just how beneficial the KIRAN environment is for improving social skills. The boys and girls in this unit have an air of confidence in their work and most feel extremely comfortable explaining what they are learning to anyone (Mr. Amil Kimar Shaya, personal interview, November 11, 2011). This confidence then gives them the confidence that they need to function more independently outside KIRAN. After talking with many of the people working in social integration the majority of them have aspirations to start their own small business and someday get married. For these people KIRAN has provided them with the skills that they need to believe in themselves and has provided them with skills which can be used to help integrate these young adults into society. The social skills and talents KIRAN gives these children and young adults really effects how well they are going to be integrated in to society and many of the children and young adults have a pretty smooth transition once they finish working with KIRAN.

SIDHI follows a structure which is very different from that of KIRAN. Because SIDHI provides home based education to children in the Sirmour area the focus is not on socialization, but providing children with disabilities skills to do some things in their lives independently. Most of the children involved in the SIDHI program do not have a lot of socialization with people who are outside their families. This lack of socialization is not due to SIDHI's program, but is caused by location. Sirmour district is a remote region in

Himachal Pradesh and the families here are much more isolated than they are in a city like Varanasi.

The majority of children who were observed in this study did not show enthusiasm about meeting new people. For most of the children it took a lot of prompting before the child would begin to interact with this person they did not know. The children felt comfortable with familiar faces and greeted them kindly, but were not comfortable with those they did not know. This statement is cannot be generalized to all children with disabilities because this is going to vary depending on the child's disability, severity, and personality, but in this district for seventy-five percent of the children visited this was the case. This lack of socialization is going to create problems when these children have to do more on their own in society. Without socializing with others these children are not going to feel comfortable interacting with people they do not know. In order for these children to have a successful integration into society they need to feel more comfortable talking with people they do now know and in order for this to happen it is important for the children to get out of their own homes more often.

In the Sirmour district there is one opportunity for children with disabilities to come together and socialize with one another. Every year there is a sports meet in which all of the disabled children are allowed to participate. This sports meet gives the kids a time to fit in and feel like all of the other children there (Mr. Sanjeev Awasthi, personal interview, November 19, 2011). After participating in the sports meet the kids are so excited about their time there. All of those who participated receive a trophy and certificate, and these trophies can be found on display in all the houses. When arriving to a house one of the first things a parent or child will do is pull out the trophy for you to see. This sports meet

provides a lot of the confidence in the kids and it gives them something which they are extremely proud of (Mrs. Tara Devi, personal interview, November 22, 2011). For these kids this sports meet is something which they look forward to everyday.

As can be seen by this sports meet the children in the district Sirmour enjoy getting out of their home and interacting with other people. For some children leaving the house is slightly uncomfortable, but being out of their home and around people who are not just family is important in gaining skills which are needed to be integrated into society. The SIDHI program does not work on the socialization of the children in their program, so it is up to the families to make sure their child interacts with other people. SIDHI does encourage parents to take their child with them to social gatherings and encourages all families to participate in the sports meet (Mr. Sanjeev Awasthi, personal interview, November 19, 2011). Encouragement is the only thing SIDHI can provide for the families because it is ultimately their decisions as to whether or not they are going to take their child.

There is a difference which can be seen in the kids who do participate in the sports meet and those who do not. Based on observation it seems that kids who participate in the sports meet are more eager to interact with their family and people outside the family. These kids seem to like having other people around and are easily excited by the presence of people who are slightly unfamiliar. The kids who did not participate in the sports meet spend the majority of their time with their family and are not given the opportunity to get out of the house that often. These kids are not eager to interact with other people and spend a lot of time finding entertainment for themselves. There are a variety of reasons which why these children do not attend the sporting events: transportation difficulties, schedule conflicts, parents are not willing to attend, and child may not be interested in going. The

reasons as to why the children from this study did not go is unknown and it cannot be assumed that a child did not attend the sports meet because their parents did not want them to be around others.

The disabled children working with SIDHI are not given the same opportunities to socialize with others like the children at KIRAN are given. As a result a large difference can be seen in the children from these two institutions. The children at KIRAN are much more outgoing and willing to talk and play with people they may not know as well. The children who work with SIDHI are much more closed off and most of them are not very open to outsiders. Socialization is an area which is very hard in the Sirmour district. This does not mean to imply that the SIDHI program is lacking, but just shows the socialization of disabled children is crucial in their development. This socialization helps provide skills which will enable them to live a much more independent life through confidence to interact with others. Through this socialization children with disabilities are integrated into society and without socialization disabled children continue to be socially excluded.

Moving Forward Towards Social Integration

Social integration of children with disabilities is mainly being held back by society's views of disabilities and people's attitudes towards the disabled. Based on the findings of this study if people in India were more accepting towards those with disabilities then social integration would not something which institutions spend time focusing their energy on. If society was accepting of those with disabilities, they would automatically be included in the functioning of the rest of society. Institutions would not have to spend time finding ways to make transitioning into society easier because people would be welcoming and willing to help those with disabilities.

Ultimately, it is still perception and attitudes towards the disabled which influence the ways families interact with their disabled child. Most parents who have a child with a disability are accepting of their son/ daughter, but the societal views on disability still impacts how much integration the child experiences. In rural areas most families of children with a disability are accepting and grateful for their child, but although they have apposite attitude towards the child the rest of the community might not. As a result of the community's views, the child is going to be kept in the house more often and not brought to events with family friends. This is the family's decision, but if the family wants people to accept and understand disabilities they need exposure to disabilities. By keeping children with disabilities hidden from the public eye people are not learning about disabilities, and thus they have no reason to change their attitudes towards the disabled. In order for change to occur families need to not worry about what people think of their child, but be willing to explain and help them understand their child's disability.

It does need to be taken into account that the information may not generalize to other regions in India. India is a very diverse country and the attitudes in one region are going to be different from the attitudes in a different region. This study was specific to the Varanasi area and the Sirmour district. Amongst these two regions there were differences in the way people viewed disabilities, so it is safe to say there are going to be other differences in other places in the country. Another reason this study cannot be generalized to a larger population is because of the small sample size. Data in the Sirmour district was only collected from twelve different families, and in Varanasi data was collected from five different interviews with the staff at KIRAN. This is not a large enough sample size to have any statistical significance. With a sample this size it is also possible that within the communities which

were examined there are opinions about disabilities which were not accounted for. To confirm the results and findings of this study a larger sample would need to be used.

Another issue which may have impacted some of the findings of this study was translation. Interviews for this study were conducted in Hindi and then translated into English. Some of the original content may have been lost during this translation process. The overall meaning be maintained through translation, but some details may have been lost along the way.

Conclusion

As India continues to progress towards becoming a developed nation the most marginalized groups, such as people with disabilities, need to be taken into consideration. India has clearly laid out the rights of people with disabilities in the People with Disabilities Act of 1995 and now the main thing holding back the disabled is their integration into society. The disabled have been hidden from public view for a while now and the social integration of these people is challenging. The main things holding back the disabled from being integrated into society are a historically old stigma and the feelings families have towards having a child with disabilities.

Negative stigma associated with disabilities has been changing in recent years as people are becoming more knowledgeable and aware of disabilities. Although this stigma is changing there are still enough people in the population who believe still let the stigma affect their attitude towards the disabled. These people are creating challenges for people with disabilities to be integrated into society. In order for complete social integration of the disabled to occur it is necessary that this stigma is no longer applied to daily living.

It is also important for families to not care about what others think of their disabled child and worry about the needs of their child. By listening to what others are saying their own child is being put on the back burner and this is causing delays in the integration of disabled children into society. When families care and put time and effort into helping their disabled child live independently it is shocking at how much the child is actually able to do on his/ her own. Families play a crucial role in the integration of children with disabilities a lot of the social integration needs to begin at the family.

Although the family plays the most important role in social integration of people with disabilities, institutions aid families throughout the process and provide families with advice on ways they can help integrate their child. Not all, but many institutions also assist in providing children with disabilities with a group of people whom they can socialize with. Access to socialization with people outside the family is important because it teaches children with disabilities social skills that cannot be learned on one's own. Institutions throughout the country need to push for the socialization and integration of children with disabilities in order for these children to be publicly acknowledged and accepted.

If India plans on emerging as a developed country people with disabilities need to stop being so marginalized, and this begins with the society changing their attitude towards the disabled. The larger population of India needs to accept, understand, and work towards creating equal opportunities for people with disabilities so the development of India can continue. Then it is through this societal change that people with disabilities will be able to have full integration in society.

Recommendations for Future Study

- Future studies should focus on what methods of social integration are most successful. By obtaining this information people will have an easier time being integrated and people will not have to guess what works and what does not work.
- Another area which is important to study is inclusive education. As more children with disabilities are beginning to attend school its important to understand what type of education will be best. There has been a lot of debate over inclusive education, but what is actually best for the child?
- Another area of study this report could use is determining if there is a difference in inclusion in rural and urban areas. Does the environment a child in which a child with disabilities is raised in impact their integration into society? This study looked at both urban and rural settings, but a comparison of the two was never done.

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