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Cultural Barriers to South Indian Families' Access to Services and Educational Goals for Their Children with Disabilities

Maya Kalyanpur, Ph.D.
Department of Special Education
Towson University
mkalyanpur@towson.edu

I.P. Gowramma, Ph.D.
All-India Institute of Speech and Hearing
Mysore, India

Abstract

Using semi-structured interviews and focus groups, a study of twelve parents of preschoolers and young adults with disabilities in India revealed the cultural and social barriers to families' access to services and their educational goals for their child. Concerns common to both groups included difficulty of accessing information on services in a culture that continues to hold traditional negative perceptions of disability and lacks the infrastructure for dissemination of information. Specific concerns related to setting educational and work-related goals for their child, as the parents of the preschool children identified "learning to speak" and the parents of the young adults "an appropriate job" as primary goals, within the constraints of a multilingual, caste-based society.

Studies on families of children with disabilities indicate that cultural factors strongly influence families' attitudes towards disability, coping and help-seeking behavior (Ingstad & Whyte, 1995). Current research on culturally diverse families in the U.S. identifies several reasons for their limited access to services and low participation in the educational decision-making process. These include language barriers, financial constraints that preclude taking time off from work or finding child care or transportation to attend meetings or volunteer in school, and unfamiliarity with the educational system that results in a lack of knowledge about service availability or legal rights (for a review, see Turnbull, Turnbull, Erwin & Soodak, 2006). The influence of culture as barriers to parental participation and access to services has also been repeated in other countries. For instance, families operating within the South African culture of apartheid and oppression were socialized not to get involved in their child's education and to abdicate their responsibility to the government (Gwalla-Ogisi, Nkabinde & Rodriguez, 1998), while Japanese mothers, immersed in a culture where the mother is the child's "second teacher", are actively involved in their disabled child's education (Abe, 1998).

Despite evidence that the concerns are very different for families at two significant life cycle stages, preschool and the transition to school and young adulthood and the transition to work (Turnbull, et al., 2006), few studies have investigated these differences in culturally diverse families. A study comparing differences in the development of self-determination in young adults in the US and Taiwan, for instance, found that while Taiwanese parents were less likely to foster self-determination in their children than the American parents, both groups identified this as a more important goal for their secondary school-age children than the primary school-age children (Zhang, Wehmeyer & Chen, 2005).

Most research on families of children with disabilities in India concludes that the child

places a tremendous burden on the family (Annapurna, 1997; Gandotra, 1991; Gupta & Singhal, 2005; Peshawaria, Menon, Ganguly, Roy, Rajam Pillay & Gupta, 1998; Sen & Tuli, 1991; Shanmugavelayutham, 1999; Srivastava, 2004). Contributory factors include lack of information, mothers' lack of education and negative attitudes among extended family members. A few studies indicate that parents also respond positively to their child with disabilities. For instance, Alur (2001) found a strong community response and support network available to low-income parents in western India, and Rao (2001; 2006) highlights the strengths of Bengali mothers in eastern India in their capacity to adjust and demand similar adjustments to their child from their communities. Similarly, studying mothers of children with visual impairments in rural South India, Jacob (2005) found that "contented" mothers relied on the tradition of support existing in their family or community, rather than success in education, to ensure the future security of their child, while "seeker" mothers believed that education was the key to ensuring economic independence through a good job or marriage. Although Sen and Tuli's study (1991) is the only one that looked at a specific age group, that of young adults, it does not identify parental concerns relating to this life cycle stage. This study was developed in response to the need to learn about the particular concerns of parents of preschool children and young adults, and identifies some cultural barriers to Indian families' access to services and educational goals for their children with disabilities.

Although the Indian government has developed inclusive education programs for children with disabilities, the provision of the majority of services continues to remain the domain of non-governmental organizations, or NGOs, in the form of special schools (Kalyanpur, in press; Rao, Narayan & Mani, 2005). Further, a study of parents' perceptions of NGO services found that although most middle-class, educated, urban parents were dissatisfied with the services they received, they still preferred to place their child with disabilities in a special school as they could afford the fees and because of the general perception that government schools offer even poorer quality education (Govind Rao & Prakasam, 2003). However, the fact remains that over 94% of children with disabilities in India do not receive any educational services (National Sample Survey Organization, 2003).

Regional disparities in economic development, differences in language, tradition, and religion further affect service provision. Within this context of limited resources and, particularly, lack of trained teachers, the involvement of parents in their child's education is predominantly perceived in terms of supplementing teachers' roles as trainers and educators for their children (Gupta & Singhal, 2005; Peshawaria, et al., 1998). For instance, in Gupta and Singhal's study (2005), families of children with autism in South India were routinely involved in the intervention program designed for the child. Similarly, training mothers was a primary objective of Seva in Action, an early intervention program in South India (Rao, 1997). On the whole, however, families are forced to care for their disabled member without any professional or technological support (Thomas & Thomas, 2002), or to spend considerable amounts of time and money in seeking services (Aluri & Karanth, 2002).

Method

Participants

Twelve Indian parents of children with disabilities were interviewed (see Table 1), using semi-structured, ethnographic interviews, to learn their perspectives on the services and educational goals for their child. This interview format is most conducive to elicit the kind of information the study sought and allow the participants to identify their own concerns (Strauss & Corbin, 1998). Although a few open-ended questions (e.g., how did you find out about this service? What sort of job would you like your son/daughter to have?) were brought to the interview and asked to start the conversation, follow-up questions were developed as it proceeded. While the preschool children attended a government-funded speech and hearing clinic, the older children attended a private pre-vocational

school, in a mid-sized city in South India. The five mothers of the young adults were interviewed in focus groups, while the parents of the preschoolers (five mothers and two fathers of five children in all) were interviewed either individually or as a couple. Parent participants were paid a small honorarium for their time. The interviews took over an hour and were conducted in the parents' preferred language. The parents brought their child to the interview. The younger children sat quietly beside their parent/s while the young adults occupied themselves with drawing and similar activities in a small group out of our hearing. For triangulation, data also included observations of parents' interaction with a

Table 1

Demographic Data on Participants

Mother's name	Religion	Language spoken	Child's name	Sex	Age	Type of Disability
Mary	Christian	English	Johnny	M	5	Speech delay and hyperactivity
Bhanu (mother) Raghu (father)	Hindu	Kannada	Ramu	M	5	Hearing impairment, mild autism
Sumitra (mother) Devdutt (father)	Hindu	Kannada	Pranay	M	4	Learning disability
Rose	Christian	Malayalam	Albert	M	4	Autism
Namita	Hindu	Telugu	Kaushal	M	5	Mental retardation
Meera	Hindu	Kannada	Rahul	M	16	Mild mental retardation, hearing impairment
Vimala	Hindu	Kannada	Vikram	M	15	Learning disabilities
Lakshmi	Hindu	Kannada	Pankaj	M	16	Mental retardation
Sushila	Hindu	Kannada	Maitreyi	F	16	Mental retardation
Ratnamma	Hindu	Kannada	Dilip	M	14	Autistic

psychologist and a vocational teacher. Field notes were maintained on these observations, which were analyzed for evidence and corroboration of the parents' concerns regarding their interactions with professionals.

All the participants ranged from middle class to affluent socio-economic status and belonged to upper castes. The mothers had completed pre-university courses at the community college equivalent; none worked outside the home. Their husbands were variously employed as managers in a bank or service-based company (one was in the Middle East), or were self-employed as owners of a small industrial company or large coffee estate. Two families were Christian, the rest Hindu. Of the ten children, whose ages ranged between 4 to 16 years, nine were male. The types of disability among the preschoolers included, with cognitive delays, autism, speech and language impairments, and hearing impairments, and among the young adults, included learning disabilities and mild developmental disabilities. The names of all participants have been changed.

Data Collection and Analysis

All the parents who came to the clinic or the vocational center during the week of sample selection were approached by the local liaison and asked if they were willing to be interviewed. All the parents chose to be interviewed outside the home and interviews were conducted with those who showed up at the focus group or individual meeting venues.

Interviews were taped, transcribed, and translated into English. Each interview was then checked for reliability of translation by a researcher fluent in both English and the original language of the interview. Data were analyzed inductively in a recursive process of constant comparison through coding and thematic analysis (Strauss & Corbin, 1998). For instance, the two groups were interviewed separately based on research that the issues of parents of preschoolers and young adults are quite different. Although this was borne out in our analysis of the findings, some common concerns also emerged.

Findings

Findings revealed concerns common to both groups of parents as well as specific to each. A common concern was the difficulty of accessing information on services in a culture that continues to hold traditional negative perceptions of disability and lacks the infrastructure for dissemination of information. Specific concerns related to setting educational goals for their preschooler and work-related goals for the young adult. The preschoolers' parents focused on acquisition of language skills as a primary educational goal, while the parents of the young adults identified an appropriate job as a primary goal. Although families around the world may share these concerns, the cultural influences of a multilingual and caste-based society provide a uniquely Indian flavor.

Barriers to Accessing Services

All the parents expressed their frustration about the difficulty in accessing services. Familial attitudes towards disability were a primary barrier, as parents struggled to overcome negative responses to atypical behavior and development. Additional barriers included negative professional attitudes in an environment that does not support parental rights and has limited infrastructure for dissemination of information about services.

Negative Familial Attitudes Towards Disability. Familial attitude towards disability was a major cultural influence on parents' access to services, magnified by the significant role family support, both nuclear and extended, plays within the Indian context, a finding substantiated in other research (Coleridge, 2000; Persha & Rao, 2003). The mothers maintained a strong emotional bond with their husbands' family, allowing their in-laws to play a central role in raising the children and influencing any decisions to seek or continue with services. For instance, when one of the preschooler's father left for the Middle East to earn more money, his parents insisted that the mother leave her older son with them and move to the city to seek services for her preschool son. Now she worried that, if the

boy failed to show adequate improvement, her in-laws might refuse to have her husband's remittance continue to pay for these services.

Many of the parents lived with the knowledge that their child was an embarrassment to their families, particularly if their child demonstrated cognitive impairments or socially inappropriate behaviors. As the mother of a preschooler said,

When guests came to our home, my in-laws warned me not to come outside with my child. They scolded me and accused me for everything he does. They compare him with other children and they say, "He is mad". Sometimes when I heard such complaints from my in-laws, I thought about committing suicide.

Support came more easily when the family could believe that the child would eventually "become normal". For example, one mother believed that her son's paternal grandparents were more accepting of him because his normal physical appearance helped him to blend in with his peers. As a result, the parents had delayed accessing services, including diagnostic visits to physicians; for fear that they might find their concerns for their child justified. One woman's mother-in-law asked her to wait when she mentioned that she had noticed some developmental problems in her 6-month-old son because to acknowledge that her grandson might have some problems was to admit failure in her lineage.

Studies indicate that these feelings of shame and embarrassment, often resulting in lack of support by extended family members, are common among Indian families (Peshawaria & Menon, 1991; Peshawaria, et al., 1998). Two cultural factors play a role here. First, the sociocentric orientation, or the emphasis on the importance of family ties that includes extended family members as well (Konantambigi, 1996), often leads to the perception that the stigma of the disability reflects on the entire family, resulting in elders rejecting the mother or the child or both. Coleridge (2000) found that Afghani families would often claim that their children became mentally retarded after a rocket attack in order to conceal the congenital nature of the disability. Second, the focus on behavioral

conformity (Daley & Seligman, 2002; Srinivasan & Karlan, 1997) places children with disabilities who manifest behavioral challenges at greater risk of rejection than, for instance, deaf children who are less likely to deviate from these expectations (Miles, 1997; Parasnis, DeCaro, & Raman, 1996). Sen and Tuli (1991) noted that the mothers in their study stopped going out for social occasions or inviting people to their home in fear of embarrassment about their adolescent son's inappropriate behavior.

Negative Professional Attitudes. Parents were also frustrated by the negative attitudes they encountered from professionals, ranging from unhelpfulness to disapproval at parents' noncompliance. In this study, the parents repeatedly spoke of service agencies that refused admission to their children on various grounds, including ineducability relating to severity of disability, or age in terms of the child being too young to benefit from intervention, and having to accept these unilateral decisions. Although parents of children with disabilities in the US may experience similar reactions from professionals, factors linked to the historical development of special education services provide a stark contrast. Unlike the US where parental participation is one of the foundational principles of IDEA that emerges from the rights-based individualistic milieu of American society (Kalyanpur & Harry, 2004), in the Indian collectivistic culture, parents have no rights, neither by legal nor by socio-cultural sanction (Alur, 2001). Albeit historically, parents in the US were forced to play the passive role of recipients of professional decisions (Turnbull, et al., 2006), legislation that mandates parent participation and a professional and societal ethos that accepts and expects parents to advocate on behalf of their child have given parents both the authority and opportunity to do so, a situation that does not prevail in India (Alur, 2001).

Among these Indian mothers, there was an implicit understanding that a parent could not be a professional, illustrated, for instance, by their frequent self-deprecatory comment that, "after all, we are only the parents," and by their initial assumption that the purpose of the focus group interview was

for them to listen and learn while the professionals talked and led the meeting. This clear divide between the role of professional and parent (Peshawaria & Menon, 1991) contrasts with the situation in the US where many professionals are themselves parents of children with disabilities, and, indeed, being a parent is a desideratum for certain professional positions involving parental advocacy. Additionally, more so than in any other country, many parents, particularly mothers, forced into the role of service developers historically, have voluntarily acquired professional credentialization.

This assumption of professional authority asserted itself in all interactions with the parents in this study, who responded with complete acquiescence. This dynamic is implicit in the situations parents described, as the following examples illustrate. Sometimes the professionals were unhelpful. As the mother of a preschooler said:

> Parents were never allowed inside to observe the therapy. Once the child is taken inside, what they do is unknown to us. (Even) when I asked, I was not told.

Similarly, a parent chose not to reveal that she saw little improvement in her son:

> Because there was no other option, even if I felt there was no improvement, I could not actually say this to the professionals. If I told them, I was afraid they would say, don't come.

The dynamic of professional authority versus parental acquiescence was more overt in observed interactions, as the professionals often adopted a bullying tone when they interpreted a parent's behavior as being noncompliant. When one mother mentioned that her husband had made several visits to the city from the neighboring home state to see her and her son, the psychologist demanded to know, "Then why does your husband never come to the Clinic?" One preschooler's mother's admission that she had three children prompted the personal question, "Why have you not followed any family planning?"

Similarly, when the mother of a 14-year-old boy stated that she planned to send her son, after he completed his school leaving certificate examinations (a diploma equivalency examination similar to a GED), to work in a factory that her sister owned because he would get the supports he needed there, the vocational teacher pointed out that the boy was an artist, suggesting that the mother was unwilling to nurture his artistic side because "her main ambition is that he must be self-sufficient and earn more money."

The parents were distressed that they often had to deal with professional disapproval that they had "delayed" bringing their child to the clinic despite obvious indications of impairment, seeing it as an implication that somehow the families were to blame. When Bhanu, describing her son's delayed developmental milestones, admitted that she "had not taken much care (notice) at that time," the psychologist scolded:

> Already you had your first son. Why didn't you compare his development with your other son? Up to nine months, you have not bothered to do anything.

While in some cases, the families had indeed been reluctant to seek services hoping to delay the bad news, in other cases, ironically, it was the professionals themselves who had caused the delay. As a 16-year-old's mother described:

> During delivery, the children's specialist was present. But he did not say anything. The child would fall sick and was severely weak. Still they did not diagnose anything.

Lack of Information. Families in developing countries like India (Aluri & Karanth, 2002; Srivastava, 2004), Indonesia (Hamid, 1993) and China (Chen & Simeonsson, 1994) have identified the lack of information as a primary concern. The process by which the South Indian parents in this study found a service that met their child's needs can only be described as serendipitous. Only one parent was a member of a parent organization and appeared to get most of her information from that source. Other parents attempted to get information from physicians and other professionals, often unsuccessfully. Indeed, despite its disadvantages, the most common source of information was the family. The uniqueness of this group becomes apparent

when one considers that other studies of middle-class participants (who are more likely to be educated) found that the more educated the mother, the more likely she was to work outside the home, facilitating her access and ability to seek out information and community resources (Hamid, 1993; Srivastava, 2004). Although the mothers in this study were both middle class and educated, none worked outside the home, possibly because of their high caste status, restricting their access to information.

Although parents of children with disabilities in the US also struggle to find appropriate services, the process of identifying these services is facilitated by legislation and much more streamlined than it is in many developing countries (Chen & Simeonsson, 1994; Hamid, 1993; Peshawaria et al., 1998). Neonatal services become available when a child is identified at risk of or with a disability at birth, while a phone call to Child Find can result in a professional evaluation to determine the type of disability and appropriate intervention. In addition, the Individuals with Disabilities Act (IDEA), the legal mandate for a free, appropriate public education in the least restrictive environment, provides further specificity of service. Stemming from the establishment of parent organizations and similar advocacy groups, parent-to-parent networks have become an integral aspect of information dissemination, among other purposes, in the US. Finally, for parents motivated to conduct their own research on what might be available, there are alternative sources of information: in order of preference, parent organizations, professionals, friends, and books and magazines in libraries (Marden & Nicholas, 1997) while, more recently, the Internet serves as a major clearinghouse (Turnbull, et al., 2006).

There were broader social and political factors that further affected these parents' lack of information. For one, legislation for people with disabilities is a recent event (for a review of these legislations, see Misra, 2000). However, none of these Acts ensures parental rights to services (Pandey, Chirimar & D'Souza, 2005). It is significant that among this group, only one mother knew of one Act.

For another, the majority of services are provided to children through private or non-government organizations that charge fees. However, regular education private schools will rarely admit students with disabilities because of the societal pressures for academic success (Premji, 2005) and the regular education curriculum is not adapted for students with disabilities (Misra, 2000). Further, most services tend to be located in urban areas, particularly the bigger cities (Govind Rao & Reddy, 2004). As a result, poor dissemination and a scarcity of resources combined to make access to services difficult.

Initially, the parents searched locally, visiting the family physician if they lived in small towns or in the remote hills. However, these rural areas or small towns either had no services at all or the services proved unsatisfactory over time. When Rose returned from the city to her hometown with a diagnosis of autism for her son, the local pediatrician "did not know anything about autism and told [her] that he was hearing this [word] for the first time." Coming quickly to terms with the lack of resources in their immediate vicinity or based on the recommendations of the local medical expert, they then cast their net wider to consider options that might be available in larger cities.

While all the mothers in the young adult group lived in the city in which the study was conducted, it is noteworthy that four out of five mothers from the preschool group had moved to it because it offered more services for children with disabilities, leaving smaller towns, some in neighboring states, or remote, rural areas. The renown and reputation of a facility drew them. They came for a short stay to avail of its "outpatient" services and then stayed on, renting a small apartment and visiting the family on weekends and over the summer. It is even more significant that all the mothers in the young adult group and two in the preschool group had further spent an extended period of time ranging from two months to two years in a neighboring metropolis, about 300 kilometers away, looking for appropriate services. This willingness to relocate in order to receive services, often at great personal cost, is not uncommon among middle-class families with a child with a disability (Mukherjee, 2003).

In summary, parents' access to services was impeded by various cultural influences, including

familial and societal attitudes towards disability, a milieu of professional authority, and inadequate infrastructure for information dissemination. The next section identifies concerns specific to each group, the parents of the preschoolers and the parents of the young adults.

Barriers to Meeting Educational Goals

Besides the common concern about accessing services, each group had specific concerns relating to their goals for their child. The parents of the preschoolers wanted their child to acquire appropriate language, or "learn to speak", to transition to a regular school while the second group of parents wanted their young adult to acquire the skills to transition to "an appropriate job." The implications of these goals are discussed within the context of the multilingual and caste-based society in which the families lived.

Learning "To Speak" in a Multilingual Society. The preschoolers' parents perceived language acquisition or "learning to speak" as the benchmark for their child becoming normal and being able to transition to regular school. The following statement was fairly typical of the mothers of the preschoolers:

> When he learns to speak and become normal, he can stop going (to the Clinic) and go to school. That is all I pray for.

However, two cultural factors complicated the situation for these Indian preschoolers. One, India has one national language, Hindi, and 18 regional languages, with each state having its own regional language (Ramaa, 2000). English, as an international language, is compulsory in schools. In South India, each of the four main states has an official language and every child is expected to learn to speak, read, and write the state regional language, Hindi, and English. As a result, although one language may predominate in a specific region or state, residents will typically be multilingual, as the official language and the spoken language may not coincide.

The preschoolers in this study had cognitive impairments that had contributed to delays in speech and language acquisition. Some of them had adequate receptive, but very little expressive language in a regional language depending upon which part of South India they came, and no knowledge of Hindi or English. Since their teachers at the preschool Clinic also came from different parts of India, they too spoke a variety of regional languages. As a national institute, English was both the medium of instruction and the one common language, so all the preschoolers were introduced to it as they learnt the English alphabet and words in English each letter started with. In some cases, a student might be placed with a teacher who spoke the same regional language, which was helpful if the child was struggling with English, but this was not always the case. This created a situation where children who had been diagnosed with language delay were receiving speech and language therapy in a language unfamiliar, even foreign, to them by teachers who did not always speak the language they were familiar with.

The second cultural influence lies in the significance that the parents did not object to their children being introduced to English, although they saw them struggling with it, because they saw its acquisition as being directly linked with social mobility. Given the societal pressure for economic success (Premji, 2005), learning English, the vehicle to better jobs and therefore a better lifestyle (Pinto & Sahu, 2001), was a natural corollary to learning to speak. As research on bilingual education indicates that acquisition of a second language prior to mastery of the first has been found to often result in children struggling to master both (Germanos-Koutsounadis, 2001), the presence of language delay can be expected to impact language acquisition further.

Finding an "Appropriate Job" in a Caste-Based Society. Specific issues the parents of the young adults raised were related to the difficulties they faced finding jobs for their children, given the caste barriers and familial stigma that placed constraints on appropriateness of certain types of employment, and the paucity of government-funded opportunities for employment for persons with intellectual disabilities. Those jobs that were considered suitable according to caste required a certain level of competency in

money management, and generated additional concerns about their daughters' and sons' safety.

Caste in India is a major determinant of a person's occupation (Beteille, 1992). Despite several governmental efforts to ameliorate its effects through affirmative action, this situation continues to prevail (Persha & Rao, 2003; Thomas & Thomas, 2002). The parameters of the caste system relegate those occupations that are considered menial and lowly, such as carpentry and shoemaking, to members of lower castes, and only those belonging to a high caste, such as Brahmin, are permitted to occupy positions of higher standing and status. When strictly observed, the caste system restricts job options for all its members whereby a cobbler may not aspire to any other profession, and, by the same token, members of high castes would be defiled if they pursued a vocation that required manual labor. What this meant for these young adults is that, despite their cognitive impairments that made manual labor more compatible with their strengths, their upper caste status precluded the possibility of pursuing jobs that would require fewer intellectual skills. Thressiakutty and Govind Rao (2001), describing the efforts of professionals to develop a transition plan for a 17-year-old boy with mild mental retardation and cerebral palsy, note that, "as the boy belonged to an upper middle class joint family having a business background, the parents were keen that his job should suit their socioeconomic status (p. 49)." He was found the job of issuing receipts, using a billing machine that could be operated from a sitting position, in his father's company.

Another limitation was that most of the government-funded programs focus on rehabilitation for adults with physical disabilities, and, additionally, are available primarily in the larger cities (Govind Rao & Reddy, 2004). In the city in which these parents lived, there was only one facility, a private agency that offered vocational opportunities for young adults with disabilities in a sheltered workshop environment. As this catered mainly to students with moderate developmental disabilities, the parents had rejected this option as being inappropriate for their children whom they saw as having less challenging

needs and benefiting from a more inclusive job environment.

A final constraint was the concern regarding their child's personal safety, as the parents felt their child's disability rendered them especially vulnerable. This reluctance, based on fears "both real and imagined" (Sen & Tuli, 1991) has contributed to the stereotype of the over-protective parent among professionals (Peshawaria, et al., 1998; Zoengpani, 2005). The mother of the 16-year-old daughter worried about the possibility of sexual abuse or exploitation:

> There is screen-printing training available, but only one lady works at the institution. The rest are gents. So it is a risky place to send a girl there.

The other parents worried that an unscrupulous public could exploit their sons. As one parent described:

> It is very easy to exploit them. The shop wallahs cheat them. Even the auto (rickshaw) drivers behave in a different way. They say, the money you have given is less (than the fare) and drop them off in some very far away places, even though he has enough money.

Identifying the appropriate job, as a result, was proving a daunting task. Options the parents were willing to consider as being within these constraints were, for the boys, managing a telephone booth, a Xerox shop, or a mechanical workshop, jobs that require money management skills and for the girls, typing which requires literacy skills. Money management, then, was a necessary prerequisite to independence. As one parent stated:

> We wish him to have a normal life. The only problem is he does not have money concepts. He goes to the shops (to run errands and buy groceries) boldly and regularly. Whatever change they give, he brings back. He can't manage change. That is his weak point. If he can understand how to count the money, he can live without others' help.

Interestingly, rather than depending upon formal networks, like the school, the parents looked within the informal, family network to find these appropriate jobs, because this way, they could ensure that the job met all three criteria of matching

the caste status, providing a safe work environment, and the accommodations and support the young adult would need. One mother was determined to find her 16-year-old son a job in her sister's factory where he would get the supports he needed, be safe, and earn enough to be independent, at the risk of defying the pre-vocational teacher who believed that, with his talents, he could become a musician – a job the mother believed was too competitive and the earnings uncertain. Another mother said she intended "to open a shop" where her son could be accommodated and supported.

Negative familial and societal attitudes and a lack of information inhibit parents' efforts to seek intervention and special education services while the complexities of a multilingual and caste-based society impede the realization of the goals that their preschool child learn to speak or their adolescent acquire an appropriate job. The next section discusses implications for professionals.

Implications for Professionals

The small sample size of this study limits its generalizability. Additionally, the fathers' separate opinions and perspectives were not elicited nor were extended family members interviewed in deference to the mothers' preference. Yet, despite these limitations, the findings merit serious consideration and have significant implications for professionals.

As Coleridge (2000) notes, any development effort must be seen through the filter of culture. Further, India is a culture in transition (Thomas & Thomas, 2002; Srinivasan & Karlan, 1997). Coleridge (2000) asserts that while modernizing influences, such as television, the Internet, mass migration and tourism have affected urban dwellers so that the global culture is manifested in superficial matters such as food, entertainment, and dress, core values, such as those relating to class, marriage, and family life, are slower to change, even in urban areas. As he puts it, "middle and upper class young men in Bombay and Bangalore dressed in trendy western clothes and designer sunglasses may still marry wives selected by their parents on strictly caste lines

(p. 25)." On the other hand, Srinivasan and Karlan (1997) suggest that these very same modernizing influences in a climate of fierce global economic competition have contributed to radical changes in child-rearing practices and family lifestyles among urban families, as traditional values of cooperation and inherent status gradually give way to the more western values of individualism and earned status. Similarly, Boyce and Lysack (2000) suggest that the difficulties parents face in finding appropriate jobs could "foreshadow increasing tensions between people with disabilities and able-bodied persons, as commercial enterprises, in an effort to improve efficiency and enhance market shares, might prefer to recruit fast-working, able-bodied employees and view job accommodations for people with disabilities to be luxuries they can ill afford" (p. 35). On the flip side, as the economy shifts towards the service sector, the upsurge in the need for soft skills, or a less abrasive interpersonal communication style that is globally-responsive (Jasrotia, 2005), may improve at least some outward aspects of parent-professional interactions, if not the current imbedded hierarchical structure and the imbalance of power.

It is crucial that professionals understand and take into consideration these larger cultural and societal influences when working with families of children with disabilities. However, the complexity of these factors does not allow for simple solutions. Attempts by professionals to become more responsive to family needs by eliciting parents' preferences for which language they want their preschool child to learn and providing instruction in it, creates some ethical dilemmas. On the one hand, driven by the knowledge that English is "the passport to the world of the educated elite" (Pinto & Sahu, 2001, p. 8), parents may choose English against the best interests of the child, while, on the other, parents who choose a regional language are closing future educational options for their child. Similarly, asking young adults what their fathers or uncles do for a living is an effective family-responsive strategy (Shevin, 1986, cited in Kalyanpur, 1996). However, while the more intellectual occupations of the middle class may not be an appropriate option for an intellectually

challenged young adult, by the same token, families may not wish their young adult to engage in a pursuit that might be more suited to his or her ability but would be deemed unsuitable by them.

How, then, is a professional to respond? Kalyanpur and Harry (2004) have suggested the need for cultural reciprocity whereby professionals engage in a discourse with families towards developing a compromise that is acceptable to both parties. A primary step would be to develop an awareness of the imbedded cultural values or the larger societal influences in professional recommendations for a service or families' preferences. This is followed by informing parents of the values, helping them to understand the consequences of their decision and allowing them the dignity of risk. Such an approach also enables professionals to avoid stereotyping parents and begin to understand the factors that influence parents' decisions and coping behavior. Learning about the parents' fear for their young adult's safety within the context of an unscrupulous public; professionals may be less inclined to dismiss this as over-protective behavior and to offer options that respond to this concern.

On a broader level, professionals can also work to create greater disability awareness towards changing negative attitudes shame as feelings of shame among extended family members and non-acceptance among the larger community (Bwana & Kyohere, 2002). This has included fund-raising and variety entertainment socials by private agencies and government-sponsored messages in the media (Thomas & Thomas, 2002). When convinced by outreach service professionals of the potential in a child with disabilities, extended family members have become more willing to (a) mention the existence of a disabled child, and (b) enroll the disabled child in a school (M.Alur, personal communication, September 27, 2005). Acknowledging the role of the extended family and involving them in positive ways, such as including them in the input process and inviting them into the classroom to observe, can help to ameliorate negative attitudes so that change can occur in small, incremental steps.

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