Education and Training in Mental Retardation and Developmental Disabilities

VOLUME 34 NUMBER 3 SEPTEMBER 1999

Going Home: General and Special Education Teachers' Perspectives as Students with Moderate/Severe Disabilities Return to Rural Neighborhood Schools — 235
SUSAN HAMRE-NIETUPSKI
SUSAN DVORSKY
ANN MCKEE
JOHN NIETUPSKI
JENNETTE COOK
CHRISTINE COSTANZA

Adaptation in Families with Adult Children with Mental Retardation: Impact of Family Strengths and Appraisal — 260
DANIEL C. LUSTIG
THERESA AKEY

An Investigation of Coping Skills of Parents of Children with Disabilities: Implications for Service Providers — 271
ROSEMARIE SCOTTI HUGHES

The Adaptive Project of Parenting: South Asian Families with Children with Developmental Delays — 281
CHEMBA RAGHAVAN
THOMAS S. WEISNER
DEVINDRA PATEL

Teacher Perceptions of Self-Determination: Benefits, Characteristics, Strategies — 293
MARTIN AGRAN
KIMBERLY SNOW
JAYNE SWANER

Sexual Knowledge, Attitudes and Experiences of High School Students with and Without Disabilities in Taiwan — 302
JENGJYH DUH

Self-management of Sharing in Three Pre-schoolers with Autism — 312
DANA R. REINECKE
BOBBY NEWMAN
DEBORAH L. MEINBERG

The Division on Mental Retardation and Developmental Disabilities retains literary property rights on copyrighted articles. Up to 100 copies of the articles in this journal may be reproduced for nonprofit distribution without permission from the publisher. All other forms of reproduction require permission from the publisher.

Education and Training in Mental Retardation and Developmental Disabilities, 1999, 34(3), 281–292

© Division on Mental Retardation and Developmental Disabilities

The Adaptive Project of Parenting: South Asian Families with Children with Developmental Delays

Chemba Raghavan, Thomas S. Weisner, and Devindra Patel
UCLA

Abstract: This study investigated family adaptation patterns to children with developmental delays, in a sample of South Asian families living in the Los Angeles area, and a comparison sample of Euro-American families. The Ecocultural Family Interview (EFI) explored similarities and differences. The domains in which differences between South Asian families and Euro-American families appear were family support (sorely missed in both quantity and quality in the United States); spousal relations (improving after the birth of the child); gender roles (clearly demarcated with women doing most caretaking); cultural identity (the US "golden prison" and "blended identity"); and spirituality (formal worship less important than a general cultural continuity). South Asian families were similar in their hope that the child's delay would somehow get better as time went on, their active service use, common educational and medical issues, and requirements to adapt work and child care. Systematically exploring what "might have been" if the families had chosen to reside in their native countries led to valuable comparative knowledge.

Imagine that your child is born five years after you emigrated to Los Angeles from South Asia; it is a wonderful moment. Your parents come from South Asia to be with you, and stay for many months afterwards, other extended kin assist you and help, phone calls and faxes fly. You participate in a birthing ceremony and prepare offerings. All the struggles of leaving South Asia, and going to school and finding work seem more worthwhile, although you so miss the enmeshed feeling of shared family life that you would now have if you were in South Asia.

Then it starts to slowly unfold: your daughter seems sick, is too slow to develop, her muscles seem slack. Eventually, you discover she is developmentally delayed without a clear etiology or prognosis. You start asking about services, special schools, medical help, aid and programs from the community. You have to adapt your future and your family routine of life to your delayed child.

How do immigrant South Asian families with such children face this task? What mix of cultural tools—tools from South Asian traditions, from their extended families, from contemporary Los Angeles and American culture—do families bring to this enormous, complex, emotionally wrenching project? How do they think about their child—that is, what are the parents' cultural models of development and parenting which are brought to mind in the course of their adaptive project?

The South Asian immigrant community currently resident in the United States has grown phenomenally in the past few decades (Saran, 1985). The Asian Indian immigrant community is estimated to reach a million by the year 2000. Unfortunately however, re-

This study of South Asian families was funded by a UCLA Institute of American Cultures grant to Weisner and Raghavan, 1995–96, "South Asian families with children with developmental delays." The study of Euro-American families with developmental delays was supported by Grants # HD19124 and HD11944 from the National Institute of Child Health and Human Development. Weisner completed this chapter while at the Center for Advanced Study in the Behavioral Sciences, with support while at the Center provided by National Science Foundation Grant #SBR-9022192 and the William T. Grant Foundation Grant #95167795.

Correspondence concerning this article should be addressed to: Thomas S. Weisner, University of California, Los Angeles, 740 Westwood Plaza, Los Angeles, CA 90095-1759.

search in South Asian immigrant communities has not matched this growth in numbers. Our report contributes to a better understanding of the trajectories of accommodation to having a delayed child in this rapidly growing immigrant group.

Developmental delays (DD) of unknown or uncertain cause can occur in speech, motor, cognitive, behavioral, or socio-emotional behavioral domains (Bernheimer & Keogh, 1988). Developmental delay is the term typically applied to a slower-than-expected rate of child development when a more specific diagnosis or etiology is absent (Bernheimer & Keogh, 1986).

Our study investigated patterns of family adaptation among immigrant South Asian families with developmentally delayed children ages 3–12. We located a pilot sample of 10 South Asian families in Northern and Southern California, and interviewed parents in their homes for approximately two hours concerning how the family has adapted to their child with delays. Parents also completed questionnaires focused on this topic.

Fortunately, we had a Euro-American study to compare our South Asian families to, the Child Project sample (Gallimore, Weisner, Kaufman, & Bernheimer, 1989; Gallimore, Weisner, Guthrie, Bernheimer, & Nihira, 1993; Gallimore, Coots, & Weisner, 1996; Nihira, Weisner, & Bernheimer, 1994). We adapted the methods from the Child Project sample, adding key questions probing specifically about what the experience of raising their child would have been like in India or other South Asian countries our families came from. We then reviewed in detail the contrasts between South Asian and contemporary Euro-American beliefs and adaptive practices.

We had expected to find what some earlier studies had found— that even after concerns appear and delays are recognized, families would select and implement changes and new practices drawn from both the cultural repertoire of family practices that is found generally in Euro-American culture (Gallimore et al., 1989) and selectively, from varied other sources, including South Asian cultural traditions. We also expected that these parents, like most families with children with delays, alter neither their basic cultural model of parenting and development, nor their core repertoire of cultural practices. Rather, changes are usually specific to the situations of their child and family.

We also knew that these South Asian parents brought some unique cultural tools to help them adapt. We were interested in extending our knowledge concerning how South Asian families used their cultural tools. We believed that there would be specific features of South Asian culture that families would use in their adaptive project in California, along with a common shared set of adaptive concerns and solutions. The common problem for all families, is constructing and sustaining a daily routine of life that has meaning for culture members, and that fits with the competencies of available members of the family and community (Weisner, 1984, 1993).

One important cultural tradition relevant to family adaptation is religion. The larger Hindu pantheon in traditional South Asian societies still serves as a binding force in much of immigrant family life (Roland, 1986; Raghavan, Harkness, & Super, 1993) and may have important implications for the socialization of developmentally delayed children just as it does for normally developing children. For example, traditional Hindu ideology holds that there are well-defined, well-differentiated, ideal paths for the development of young girls and boys (Kakar, 1982, 1990). Several ideas within families regarding what is "normal" for a child to do or not to do, has its basis in this larger Hindu orientation. It is not uncommon for parents to illustrate ethical principles with reference to mythical or religious characters from the Hindu pantheon. Thus, the daily routines of children and parents in families with children with disabilities may be constructed around the idea of helping attain Hindu ideals that seek to reinforce the larger Hindu ideology for the child. So for example, delayed and normally developing children are alike in South Asia are expected, upon waking up, to participate in family worship sessions (*pujas*), eat vegetarian food, learn Vedic chants (*shlokas* and *mantras*), etc. Depending on the severity of the child's delays, girls and boys living in South Asia have regular chores assigned to them: girls with delays, just like other girls are expected to rise early, clean the courtyard, paint the courtyard (with *rangoli*, or colored powder with which women make geometric designs), help with cooking, wash dishes, put away plates, clean up after meals, etc. If the delay is not very severe, these girls go to school, but are not expected to perform exceptionally well in their schoolwork. This pattern is most common among upper-caste Brahmin families.

Accommodations in these families may not be vastly different from those in families with non-delayed South Asian children. For instance, young, Brahmin boys with disabilities will follow similar trajectories: They will go through a "thread ceremony" (that marks their entry into the first stage of their life-cycle, *Brahmacharya*) at age 6, and will be expected to go through the rest of the stages of their life-cycle in the same way as non-delayed children. It also appears that there is an overall emphasis on the appropriate fulfillment of gender-related expectations, derived from a larger, predominantly Hindu ideology for both non-delayed and delayed children.

Our report describes how the South Asian families in our sample adapted to their child across different domains of family life, and systematically compares those features to the Euro-American families in Project Child. Several key differences between the two samples stand out: (1) South Asian families miss extended family arrangements and the kin help that they have a hard time finding here. (2) Lack of social support and culture-sensitive child care pose big problems to family adaptation in these South Asian families. (3) Our study participants report that Hindu or other religious and spiritual themes are salient to them in certain situations. (4) They find services and care in the United States rich compared to South Asia, and realize that more than likely, there would have been nothing remotely comparable available there. (5) There is a gender role division of labor reported, with mothers home with their children, accepting more easily (they told us) the costs and advantages of such a choice. (6) Spousal relations are reported to have improved in nearly all South Asian families in our sample, as a result of having their child with delays.

Method

Sample

Physicians, teachers and other providers of services for children were contacted who might have knowledge of South Asian families. These providers were asked to contact families they know who might be interested in participating. The families then contacted us directly, or, if they preferred, after having talked with their provider of services. Another source of recruitment was through informal, personal contacts. We briefly screened families for appropriateness for our study (for example, are they in fact from a South Asian background, are their children ages 3–12?), briefly described the study, and asked if we could make an appointment to visit.

It was not easy to locate an appropriate sample. We made numerous phone calls and personal, word-of mouth and mail contacts with close to a hundred families. Most families that were contacted appeared to be unwilling to participate, either because of a reluctance to discuss what they perceived to be a negative aspect of their child's life (i.e. developmental delay), or out of some previous negative experience with research studies in general, or due to some experience with interventions that promised therapeutic miracles with their children.

This recruitment process led to some useful knowledge. Families often brought up their view that open discussions about developmental delays were rare and uncomfortable in most South Asian communities. One mother, in a phone conversation with one of the investigators, stated that her in-laws and her husband were opposed to any discussions about the daughter's developmental delay because of fears that a suitable marriage could not be arranged for her later.

Sustaining participation by these families and ensuring that they followed through with our interviews and home visits also presented a slight problem. Some families refused to do the questionnaire or participate in ethnographic observations, but wanted to do the interview. The reasons advanced for this reluctance were wide-ranging: They included family or personal circumstances, or inability to "find time." Some families thought that no

research study of any kind was going to benefit them personally in any way. Eventually, a sample of 10 families was identified. This group is representative of all families who were contacted in terms of their demographic characteristics, but unusual in their willingness to participate in the full research visit, both questionnaires and interviews/home visits.

The sample mothers ranged in age from 25–37, and the fathers from 28–40. All the parents in the sample had at least a high school level education, with 7 mothers and 8 fathers completing a college degree. Eight out of the ten families were in a combined family income range of $25000–$45000 per year. One of the families was actively involved in an extra-curricular activity (the father and the mother were both lead actors in a drama troupe) which they thought brought them more financial and emotional satisfaction than their mainstay professions: enough to motivate them to build a home in their country of origin as part of their retirement plans. Nine out of the ten families had lived in the USA for over 6 years prior to the study, and the tenth family had lived in the USA for three years at the time of the study.

Most women in the sample greeted the interviewers dressed in traditional Indian garments, usually the long and flowing pants and tops, rather than the 6-yards of traditionally draped fabric (the sari). Several of them had bindis (caste marks) on their foreheads, and sometimes, two religious marks (kumkum and vibhooti) on top of that. They usually wore their mangalsutras (the wedding necklace), anklets and toe-rings (the traditional symbols of a married woman). The men wore western clothes for the most part. Children's attire was predominantly Western, with the exception of days when the families visited temples, or religious/worship days. The homes represented blends of both cultures: Most of the homes had a special puja room (a place of worship) with pictures of Hindu Gods featuring prominently. All families ate primarily South Asian food at home, and observed Hindu traditions and rituals in the United States.

Procedure

Our methods were chosen for our purpose of exploring parents' beliefs and practices in cultural context. These methods offer considerable depth of understanding, breadth of coverage, concrete stories and family activities understood in context (Weisner, 1996).

A 2–3 hour Ecocultural Family Interview was done in the home, and parents completed questionnaires. The format of the Ecocultural interview is open-ended and conversational. The interviewer insures that all topics are covered but allows for a free-flowing discussion. The topics in the interview are reviewed in the Results sections below. The questionnaires include demographic information, a checklist of the self-help skills the child has learned and does around the home, and a checklist which asks parents to check off any problem behaviors the child may show. We also asked parents to complete a brief questionnaire describing typical reactions to everyday situations and problems, goals for the child, beliefs about child development, and uses of services.

Qualitative analysis of our exploratory sample was undertaken using standard procedures for thematic analysis of case materials, in order to address the following central concerns: What accounts for differences in routines, practices, and beliefs of parents living in the United States as opposed to living in the native South Asian countries? What aspects of the immigrant experience supported or made more difficult, accommodation to having a child with developmental delays?

Results: Principal Themes Across Varied Domains Of Family Adaptation

Services ("In the US you can quick-fix anything [she smiles]")

Services include screening and diagnosis, medical, orthopedic, preschool and school special education, and parent support groups. In comparison to nearly all the local communities in South Asia, from which our parents came, services in the US, along with whatever improvements might be desirable, are at least available in some form.

Nine of ten mothers rated services here in the US as excellent: It is one of the reasons that they would continue to live here. For example, one mother has this to say about services in the US:

> There is a different program that we have to enroll (W.) in, you know, they could take her on field trips and all that. So I am happy with what she is getting. She used to be uncontrollable. Now she is much better, you know, more disciplined, and more controlled. She is calmer.

This mother thinks that she would be happier if she could only get some more free time for herself, her husband and her second child.

> Like baby-sitting, you know. If we were to go back to [her home in Sri Lanka], yes, we could get some household help, and she could stay with [relatives] But I still don't want to go back particularly, because we may not find as good schooling facilities as here. Otherwise, we have to put her in a boarding school or something, you know. Actually, sometimes I like the idea of her being in a boarding house. I was in one, you know. But in Nigambu, there is nothing, we have to go to Colombo for that. If we could not find a school for W. there, we have to do what is best for her here. And that is hard to say you know. I honestly don't know what I will do.

So the situation is viewed as being very different back home: While programs and educated caregivers sometimes are available in South Asia, parents in the U.S. are dissatisfied with the resources, materials, and equipment available for children with disabilities in South Asia. One mother summarizes this idea in her description of a trip back home to Madras, India:

> When we visited India, we visited a facility headed by Dr. R., he is a leading psychiatrist in Madras. The school is mainly headed by his wife. And a kid we know has done quite well. Actually India has quite a few programs as well. They actually have entered even the Special Olympics . . . they have the child entered in the Olympic Swim Team, and there was a cover page of her in *Ananda Vikatan* (a popular Indian magazine) or something.
>
> You know—the usual Indian *concern* and *patience* for children shows through. The only thing lacking is facilities . . . the rooms are dark, all the children are crowded into one room with a wooden bench. And the teachers teach in Tamil, absolutely no English. They have *Bharat Natyam* as part of their curriculum. But the teachers would sing "Twinkle Twinkle Little Star" in their Indian accents, S. [their child] would just take off on his accent, and the teachers would be like, "AHHH . . . See how well he speaks English, see the difference between the USA and India." But I saw the difference in *learning.* Here in S.'s (California) school, he is shown visual aids, and they all get to work on computers. In India, there are absolutely no facilities, not even the bouncing balls that they need to work on to develop their muscle tone. So in that aspect, if I think, what kind of education would he get, the answer is not very good.

This mother continues to compare poorer Indian schools with the "fantastic" schools here:

> I do think that schools here are fantastic. Here, they *have* to learn to do things on their own. In India, if a special needs kid carries his books, people are like—"Oh no, don't do that!" So, services in India are very poor. You know, one of those battery operated toys, where you push some buttons, and it says Push A. . . . a very common toy here, but I went to a school there for kids with special needs, somebody from the US had donated it, and would you believe it was under lock and key—they take it out only during the physical therapy session and kids can play with it for 5 minutes maybe. And it was taken from the case, and given to S. to play with freely, because we were from the United States. It was pathetic to see something like that. I think the Indian teachers are qualified in that they are able to teach with the same amount of patience that these people here have, and they can teach the same amount of things that teachers here do, but there just are no facilities. For one, they don't teach phonetically. In one particular school, adults there that have Downs Syndrome make their visual aids for children on paper, and then they have to be laminated. They have a workshop, which is like a factory—absolutely no motivational colors in there, they don't even have markers to color.

In a similar vein, another mother reports on a disappointing experience with hospitals in India. Her child has seizures that are sudden and unaccounted for, in addition to being delayed on all fronts. The parents have had occasions where the daughter fell sick, and

> . . . here in the hospital, they watched her, even did a spinal tap. The hospital that I took her to in Bombay one time, was so bad . . . it didn't even have water, I was afraid she was going to catch some kind of other infection. The doctors are not there on call. The pharmacy doors are locked, you have to bang on the pharmacy door . . . that's what my husband did, he banged on the pharmacy door, tried to bribe the guy . . . Nurses are from the slums. Forget about medical knowledge, they don't even have basic education. . . . You are actually dependent on your *fate*, not medicine, as to whether you are going to live or die.

Religion and Its Role in Parental Belief Systems ("the 'heritage' ideal")

For all but one of the families, organized religion and daily rituals at home, surprisingly do *not* seem to play a very significant role in family adaptation as far as specific practices are concerned. One mother feels, for instance: "I think I have become stronger within myself as the years went by. . . ." She does not rely much on religion to help her. Some see religion as having disappointed them or led to their disillusionment. The following narrative is an example. Religion for this mother is important as a belief in a higher spirit, and a as way of identifying with Indian culture, but not a *means* to find specific alleviation of the sufferings deriving from their child's condition.

> My in-laws were with us then (when they discovered their child's delay). They were very supportive. They used to pray. I didn't want to pray because I didn't believe that God would help. And I removed the pictures of *Muruga* (a Hindu God) and all that and simply closed up the room. My mother-in-law had her own little idol but that was that. We viewed it as a scientific thing that happened, this [religious stuff] is all superstition nothing else. So I never prayed.

Later in the interview, this same mother clarified the social nature of religion in their lives:

> I am a dancer, and Indian dance is very closely connected with religion. I light the *vilakku* (the lamp lighted for prayers) and keep the *puja* (room of worship) door open.

Parents value the social and educational impact of native Indian gatherings, and temples. They see these contexts as "schools of heritage" and native culture for their children, and see these situations as providing intrinsic cultural education for their kids. This is very different in their communities of origin, since for most parents, religious education would come from daily *domestic* practices, not only from organized group activities. The next excerpt from a fieldnote interview illustrates the idea clearly: This family was visiting India a few years ago, and the 9-year old child with delays accompanied his parents as part of a routine visit to the temple.

> This time we went to India, we did a *Ksetradanam* (Pilgrimage), and S [their child] was fascinated by the *Muruga* altar in the *Tanjavur* temple . . . there is so much serenity, and there was something that overcame S . . . so that he just walked in there and they started the *Kandar Shasti Kavacham*. . . . (a Hindu chant). He would not get up from there. He just watched the whole *abhishekam* (the ritual washing of the deities), he sat there until the end, and we had to force him out of there. After that, he started enacting the entire scene and would not let my husband or me move from there.

The mother interpreted this visit as being very educational (not primarily spiritual or religious) for her son: she feels that he is learning the social and cultural relevance of rituals such as these in the lives of the members of his community.

Another mother echoes a similar viewpoint. The family is Christian, from Sri Lanka: "I used to go to church regularly. But after she was born, only once or twice. She was uncontrollable, and I didn't have much time. We couldn't keep her in one place, you know." When the parents heard that their daughter was autistic, the mother went and prayed a lot. "Sometimes I would go to Church, light candles and pray. Not during Service, but just regularly." She thinks that religion is very important to her child's growing up due to the parents' faith, but not for her child with delays, though, because "she wouldn't understand. If I were back in [my home town], everybody would go to church regularly. . . so that would be nice."

One mother felt that her delayed daughter's early recoveries from her medical catastrophes were due to divine intervention and were a result of prayers to specific temples in India. This family had a particularly stressful experience in that their child underwent a series of physical ailments (including blindness), agonizing medical testing, an inordinate number of waits for medical results, and a sense of hopelessness and frustration.

> Meanwhile the basic tests were all over, and they were going into minute details. Every day was bad, it was like what will today bring. My husband was a great support at that time, even at that time, he would say, "Nothing will happen to her, have faith in God." I could only cry, tell my parents and tell everybody. We had figured out, by then, (about when she was 10 months old), that something was seriously wrong. A person used to come home every day and would teach us how to deal with her. From where I got the strength, I don't know. . . . The pediatricians and other medical personnel started giving up, they told us that our girl has about a maximum of 3 months to live. They contacted Kaiser Metabolic Center, and took spinal fluid for testing to UCLA. . . . And, I kept on having faith. . . . my husband's supervisor came to see us that evening. She was feeling bad, and she wanted to pray for her. So she starved the whole day, and she came that morning and did that prayer for her. I had also vowed to temples. [A vow is typically an offering of some kind to the Gods—either a strenuous hike to a temple in the mountains, or head shaving, or offerings of fruit or money if the problem can be successfully overcome.]

In this case the doctors did come up with some medication, the expert from UCLA recommended a new medication that finally worked, and their child recovered from her physical ailments and is now termed a case of "Global Delay." The mother sees this recovery using the new medicine as an act of her faith, and views this faith as an important source of strength in raising her delayed daughter. This personal faith, which is seen as the source of her strength is something that the mother learned from members of her family, and brought here to the United States with her.

> That night I gave her two spoons of this medicine. Two o'clock, she woke up, made some noises with her mouth and looked around. At this time, she didn't see, she was still blind. But she didn't sleep for the next 24 hours. And that continued. A few days later, I called the doctor and told her that I was seeing enormous changes. A week later, I took her, and they couldn't believe it. She was cured. The test results confirmed this when we were there. It's all God's grace. And then one by one, she started crawling, walking etc. . . . My father, back in India, did something similar, made vows to the temple.

It is interesting to note that the mother continues her family's religious practices as a source of strength in the United States.

> My father, over there, on the other hand, was going to all the temples and all that. Here, in my mind, I was making all those "promises" [vows to temples] that I would do this and I would do that, and come to temples like *Tirupati*, and do *mottai* for her (shaving hair). I made the vow that I would send my husband to *Sabarimalai*, *Guruvayoor*, etc. (places of pilgrimage) . . . She was a rebirth for us. We believe that it was a miracle. Even now, I get frustrated and all that. She is going to be delayed, you know, and she is a girl. I worry more now because as she gets older, she has to be alone. It's not that we are going to be with her all the time. Especially because she is so good-looking . . . people say that all the time, but inside I am all worried. I don't think about it, but my day is gone basically. The only thing is to have faith and go along. Have faith, my husband always said. He grew up in Calcutta, so he had great faith in

Kali [the goddess]. So we used to pray every day. . .

Social Support ("... this lonely U.S. life ...")

Social support that was quite different for most of our South Asian families living in the United States than it would have been in countries of origin. This mother is typical:

> There in India, my parents (our delayed child's grandparents) had hired three servants, one girl would come take care of her till 12 o'clock, then her mother would come, and do some part-time cooking and cleaning. So none of us were burdened. I was free to come and go, I was shopping, I was out of the house a lot, or would just sit down and talk to my father. My father says even now, "you can come back, you can make it happen [to return to India with their child] if you want."

Most mothers report feeling very lonely and *socially unsupported* in the United States. All of the families expressed the opinion that this would be very different back home—they would have had continuous help with caregiving in the form of neighbors and family and friends, as well as hired nurses. One mother felt that all this care her child experienced while in India had actually helped her child's cognitive development.

However, most mothers acknowledged the social and emotional costs of having this kind of support. Two mothers felt that in-house in-laws are less useful than having people live close to you and visit, yet who do not share the home. These two families had live-in in-laws and appeared to have (from our home visit) and reported having greater stress. For example,

> At the time the MRI results came out, in two days, my mother-in-law was leaving, and I was so scared. I was like, don't leave me. . . like I got really upset, because, they just left me. My father-in-law told me, "all these days, we were taking care of those kids, so it is not possible for us to stay here for a long time, why don't you come stay with us [in India]." And that was not possible because we were going through all these tests and everything. I cannot go stay somewhere, so they just left me. At this time, if you don't get the moral support, you feel so frustrated. But my husband was like, it is our child, and we have to learn to take care of her.
>
> I really miss my parents. They would have helped if I had been in India, but then my child would become the [subject of] talk . . . you know, oh, your child has a problem and all that. Even now in India, I feel when I go to social functions and all that, and see somebody who has a child her age, I feel for that child since there is always gossip and talk. But our child has an advantage in a way, since nobody would ask much, since people think that she came from here in the US, she acts different in India for that reason.
>
> I am not sure how any of this would change if we were to live in India. We don't know too much about that. But one thing I notice is that, my daughter does much better *there*. People notice a difference when I get back here. That is why I am going to India again this time. We had plans for going back to India earlier, but now it scares me, because of her. What risk will I take? How can I be sure I will get any services? The doctors say she will be fine with medicines, slowly, over the years, she can be normal. But its scary. . . . Even though last time everybody was saying, she is so much better over there. Because you know, there were so many people coming to and fro. My father used to spend hours teaching her, playing with her. She learned a lot in Tamil, though. Then she came back to this lonely U.S. life, from Monday through Friday, everybody busy. Even the school felt she had improved while staying in India.

Another source of concern perceived by these parents was the social and cultural stigma associated with acknowledging and supporting a "non-normal" child, back in their Indian home communities. There is simultaneously a certain harsh stigma in the South Asian responses to children with delays, along with a greater ease of social support and care in South Asia. One mother had the following examples of stigma and lack of understanding:

> In India, relatives etc. do not understand that this is not a flu that can be treated. They say, "Oh, he is not cured yet—"and that makes me mad. These are educated people we were talking about . . . "Can't you do a blood transfusion," they say. In the US you can quick-fix anything [she smiles]. We had a cousin visiting, and so she came here to California. She said hello to my daughter and called her beautiful and all that. Then my [delayed] son came with his toys and sat very close to her. All my son said was, "Hi, how are you?" He expects the other person to say, "Hi, how are you?" back. When he touched her, this woman (my cousin) just shied away, like that. I was like, well, dinner is served can we go. I do not like my son being treated like that. So that's how it is, that is how my relatives are in India. So I don't take my son to my relatives' houses in India.
>
> Of course, my younger sister in Madras just adores him. But I don't take him anywhere else. My cousins ask me "Is he still slow? What is his age?" In Tamil, they ask me to tie a cradle in a temple to make him feel better. That is fine you know, it does show concern. But sometimes I just get angry, I don't get hurt. My older sister and I visited at the same time. Her boy is younger and nicer looking and all that, than my son. One musician walked in, picked up this boy and played with him. Both boys were sitting there. Then he asked me in Tamil, "Is this boy slow? Why is he so dull? Doesn't he talk?" I didn't know what to answer him.

Such difficulties were also described by other mothers: unsupportive comments by others when there were public outbursts by the children, parents' inability to openly admit to the delay because of possible social stigma, and inability to "let go" and enjoy oneself at parties and group gatherings.

Domestic Tasks and Responsibilities

All the mothers in the sample did most of the cooking and did more household work than their spouses. They appear to have few concerns relating to this issue—at least they reported none. They seem accepting of and content with husbands being the primary breadwinners, and feel greater responsibility than their husbands for bringing up their children with delays. Two mothers in the sample felt that this somewhat stringent gender division of labor was actually "good" because it caused fewer conflicts within the family.

Of course, there may be a selection effect in our sampling in that families with high spousal conflict may not have agreed to participate to the same extent, and even our participating parents may have shown a possible reluctance to discuss some aspects of conflict in close relationships.

Jobs and Economic Resources

Fathers are primary breadwinners, and these families are largely middle to upper middle class. Mothers were employed part-time or not employed at all, and told us they were happy with that situation. Economic reasons (e.g. costs of childcare) and emotional reasons (e.g. parents' fears that they can't trust their children with strangers) make most mothers stay at home and not work in the United States. They feel that this would be different back home in South Asia, since most mothers *can* work in their native countries, because of the amount of household help available.

School-Home Parental Involvement

Most mothers do *not* spend much time in their children's classrooms. There was one mother who reported spending a lot of time in her daughter's classroom, more as a break for herself than for any possible benefits she saw to the child's development. This wouldn't be too different from the situation in South Asia, according to most mothers. But mothers said that if they returned to South Asia they would miss the IEP (Individual Enrichment Programs) that the Regional Center services systems offer in California.

Childcare

Most mothers feel that it is very difficult to find quality childcare here in the US. Some mothers felt that visiting friends of similar cultural backgrounds is more important than even integration with school programs. One mother volunteers her time in a local Indian

organization to help her children integrate better with the community, and to "develop contacts" for her children—rather than because she wants to personally get involved. This is related to the "heritage" ideal we described above that growing up in the U.S. their children would miss the "essence" of their South Asian home countries and culture, and consequently miss their native value systems.

Connectedness with Spouses

A certain amount of strain in the marriage was perceived by all mothers. But as we described above, with the exception of one, all mothers reported feeling *more* connected and bonded with their husbands, due in part to having a child with developmental delays. One mother summarizes the dominant viewpoints in the following excerpt on the traditionality of sex roles: "I am happy to be left to do the cooking and cleaning; in fact I think my husband messes up things. This way we know what each one of us is doing and there is less tension, so we feel closer in our marriage." As with our data on gender roles, however, there may be a selection effect in our sampling, and a possible reluctance to discuss some aspects of close relationships.

Personal and Cultural Identity: "Blended Identity," and Feelings of Fear and Threat in the "Golden Prison"

This is an interesting and complex domain for South Asian parents. While mothers seem to advocate independence and self-sufficiency as developmental goals for their children, these goals appear under the umbrella of "Indian cultural value systems." For example, a Sri Lankan mother who described at length how she wanted her daughter to be able to do things for herself, is also of the opinion that the girl should develop a "predominantly Sri Lankan identity." When asked to clarify this idea, she said, "Well . . . I want her to. . . . I can't explain it. [Thinks for a long time.] I want that she respects her parents you know, and things like that which you don't see much here."

Another mother expands this idea further. This is a family that intends to go back to India and live there, and is very concerned about developing self-sufficiency in their son:

> Now, we have found a group of friends in India that have lived in this country for 15 or 16 years and have moved to India. One of the partners in construction management in their company has a daughter who has trained in Special Ed here. So those are the only places we visit in India. We have a network already. Right now, he is cute . . . growing up he is not going to be cute. So he should have some people that he knows when we go there. . . . Relatives here are not very supportive either.

The extent to which parents emphasize this "blended identity" is evident in the following excerpt in which this mother, who has placed great emphasis on *independence* as a developmental goal, organizes her child's daily routines: "At home we used to talk with her in Tamil exclusively, and at school she doesn't understand. We do *puja* at home, we make only South Indian food, so she is used to that." Another mother describes her son's exclusively "Indian habits":

> I don't like this country in some senses, you know. *We are in a golden prison,* [emphasis added] like my husband says. All of us are US citizens, and we have made enough money. If we go back to India, we can live like celebrities do here, you know, with 3 servants in the house, three cars, marble inlays and all my interior design dreams come true. But I am not the type to sacrifice my dreams for the sake of the children, no!!! To a certain extent, make them comfortable, yes . . .
>
> My daughter learns vocal *carnatic* music, and dance. . . . My son would not touch American food for a while, so even if I had to go to an exam I would come back and cook. He would want *sambar, rasam, kootu, pachadi,* etc. (South Indian foods). He would want *Iddly* and Chutney for breakfast, finally I said forget it! But he is totally Indian in these ways. He understands Tamil, speaks two languages. Considering all that, I would go back to India. I would probably go back and set up my own business. We have a beautiful plot back in Madras, near the beach.

Decisions regarding developmental goals for children are facilitated for many families by organizing the child's routines in specific South Asian ways, such as ensuring the child's participation in religious activities, speaking in native languages at home, cultural and group festivals and functions, 'developing contacts' and friendship networks, and food and other commensal practices. While the slant is towards providing a family ethos similar to the one that parents themselves grew up in South Asia, there appeared to be a marked awareness of issues that are unique to living in the United States (such as restrictions on dating for girls).

Commonalities and Differences with Euro-American Families

The use of the Ecocultural Family Interview (EFI) with both South Asian and Euro-American families provided suggestive empirical data on the extent to which the immigrant experience is similar to or different from that of non-immigrants. The evidence suggests that South Asian immigrant families differ from the US families, but only in specific domains. The domains in which differences between South Asian families and Euro-American families appear were *family support* (sorely missed in both quantity and quality in the United States); *spousal relations* (improving after the birth of the child); *gender roles* (clearly demarcated with women doing most caretaking); *cultural identity* (the "golden prison" and "blended identity"); and *spirituality* (formal worship less important than a general *cultural* continuity).

Our results also indicated some interesting commonalities with data from the US families: All the South Asian families, like the majority of Euro-American families in Project Child, expressed a great degree of hope that the child's delay would somehow get better as time went on. Parents generally used, needed, and even were poetic about the importance of services for their children in the U.S. Educational, medical, and specific family adaptations were similar to those found among Euro-American families.

While eight out of ten families expressed satisfaction with services and facilities in the United States, issues such as lack of personal and familial social support and lack of "culture-sensitive" childcare and other activities make the experience very different from what "might have been" if the families had chosen to reside in their communities of origin. Connectedness in spousal relations also seemed closer: nine out of the ten families interviewed reported a feeling of *greater* connection with their spouses after the birth of their child, in part because of the child's delay. Relatively clear and agreed-on gender role definitions, and relatively helpful support networks were described as sustaining the quality of their marriages.

Conclusion

The study sheds light on the experiences of South Asian immigrant family accommodation to having a child with special needs, and points to the value of developing appropriate methodologies for the study of immigrant populations. Such methods include purposive, culturally appropriate conversational interviewing. It proved very useful to explicitly raise the contrasts between South Asian and Californian cultural contexts as a part of fieldwork. For example, each topical area and domain in the interview covered both current circumstances as well as hypothetical situations which *might* exist if the family were in South Asia or chose to return there. For instance, we always asked, "If you were in [your home country] now, what might your situation be like." We found that the Ecocultural Family Interview can be used with South Asian families, and we have demonstrated that specific modifications to its use elicit valuable data on cultural issues in the South Asian community, as well as eliciting common concerns we believe are shared by all families. It is essential to take seriously the varying ecocultural circumstances, and cultural models of delay and development that are important to every cultural community. However, it is not necessary to start over in understanding family adaptation when studying each new community, because families share many common adaptive concerns.

References

Bernheimer, L. P., & Keogh, B. K. (1986). Developmental disabilities in preschool children. In B. K.

Keogh (Ed.), *Advances in Special Education, 5.* Greenwich, CT: JAI Press.
Bernheimer, L. P., & Keogh, B.K. (1988). Stability of cognitive performance of children with developmental delays. *American Journal on Mental Retardation, 92,* 539–542.
Gallimore, R., Coots, J. J., Weisner, T. S., Garnier, H., & Guthrie, G. (1996). Family responses to children with early developmental delays II: Accommodation intensity and activity in early and middle childhood. *American Journal of Mental Retardation, 101,* 215–232.
Gallimore, R., Weisner, T. S., Guthrie, D., Bernheimer, L., & Nihira, K. (1993). Family response to young children with developmental delays: accommodation activity in ecological and cultural context. *American Journal of Mental Retardation, 98,* 185–206.
Gallimore, R., Weisner, T. S., Kaufman, S., & Bernheimer, L. (1989). The social construction of ecocultural niches: Family accommodation of developmentally delayed children. *American Journal of Mental Retardation, 94,* 216–230.
Kakar, S. (1982). *The inner world: A Psychoanalytic study of childhood and society in India.* Delhi: Oxford University Press.
Kakar, S. (1990). *Intimate relations: Exploring Indian sexuality.* Chicago: The University of Chicago Press.
Nihira, K., Weisner, T., & Bernheimer, L. (1994). Ecocultural assessment in families of children with developmentally delays: Construct and concurrent validities. *American Journal of Mental Retardation, 98,* 551–566.
Raghavan, C.S., Harkness, S. & Super, C.M. (1993). *Parental cultural models of female gender role identity: Beliefs of Asian Indian and Euro-American mothers,* Unpublished doctoral dissertation, The Pennsylvania State University.
Roland, A. (1986). The Indian self: Reflections in the mirror of American life. In R.H. Brown & G.V. Coelho (Eds.), *Tradition and transformation: Asian Indians in America. Publication # 38, Studies in Third World Societies.* Williamsburg, VA: College of William and Mary.
Saran, P. (1985). Asian Indians: Demographic, behavioural and attitudinal profile. In P. Saran (Ed.), *The Asian Indian experience in the United States.* New Delhi: Vikas Publishers.
Weisner, T. S. (1984). A cross-cultural perspective: Ecocultural niches of middle childhood. In A, Collins (Ed.), The *elementary school years: Understanding development during middle childhood* (pp. 335–369). Washington, D.C.: National Academy Press.
Weisner, T.S. (1993). Siblings in cultural place: Ethnographic and ecocultural perspectives on siblings of developmentally delayed children. In Z. Stoneman, & P. Berman (Eds.), *Siblings of individuals with mental retardation, physical disabilities, and chronic illness.* (pp. 51–83). Baltimore: Brooks.
Weisner, T.S. (1996). Why ethnography should be the most important method in the study of human development. In R. Jessor, A. Colby, & R. Shweder (Eds.), *Ethnography and human development: Context and meaning in social inquiry* (pp. 305–324). Chicago: University of Chicago Press.

Received: 5 January 1998
Initial Acceptance: 15 March 1998
Final Acceptance: 10 October 1998

Education and Training in Mental Retardation and Developmental Disabilities, 1999, 34(3), 293–301
© Division on Mental Retardation and Developmental Disabilities

Teacher Perceptions of Self-Determination: Benefits, Characteristics, Strategies

Martin Agran
University of Northern Iowa

Kimberly Snow and Jayne Swaner
Utah State University

Abstract: Despite the current interest in promoting self-determination and student-directed learning, the extent to which students are systematically taught these skills remains uncertain. The purpose of this study was to survey the perceptions of a sample of special educators on the benefits of self-determination, the characteristics associated with it, and the strategies used to achieve it. Results indicated strong support for self-determination instruction, and the teachers reported that it provides numerous benefits. Despite these findings, it was noted that relatively few educators include self-determination skills in IEPs. The implications of these findings are discussed.

Concurrent with the movement toward providing students with full opportunity to participate in typical educational experiences, there has been a realization that to ensure that relevant and meaningful educational experiences are delivered, we must maximize the participation of students with mental retardation in decisions in school and in the community that affect their lives (McDonnell, Hardman, McDonnell, & Kiefer-O'Donnell, 1995). Consequently, students need to learn that they can serve as their own "supports." By using self-determination and student-directed learning strategies, they can have greater control over their own lives and the management of their behavior. This will provide students with increased competence and respect from others (Lovett, Pierce, & Harding, 1994). Like inclusion, this realization–the need to promote self-determination–is impacting educational practice.

Self-Determination

To maximize active student involvement in their learning, a self-determination or student-directed learning approach has been suggested. This allows students to be active participants in their own learning and to assume more responsibility for their own behavior. Rather than continue to rely upon an instructional model in which the teacher is given full responsibility for determining when, what, why, where, and how a student will learn, we are beginning to realize that there may be marked advantages in having the student more actively involved in educational decision making, as well as the delivery of the instruction itself.

Historically, special education programs have relied on an educational model in which teachers have been given full responsibility for making all the major educational decisions for their students, thus denying them opportunities to participate in their educational programs in any meaningful way. For many educators, this is ironic because the ultimate goals of education are to promote the independence, active involvement, and commitment of students to their learning and self-development. Instead, the role of students has essentially been to respond to a cue or receive a consequence delivered by another. Mithaug, Martin, Agran, and Rusch (1988) raised similar concerns:

> Special education teachers and others . . . are in charge. They control the entire teaching learning environment, from setting classroom and student expectations for performance and determining what tasks the student will perform to the allocation of

Correspondence concerning this article should be addressed to Martin Agran, Department of Special Education, University of Northern Iowa, 158 Schindler Education Center, Cedar Falls, IA 50614.