

Cultural Models of Transition: Latina Mothers of Young Adults With Developmental Disabilities

ROBERT RUEDA

University of Southern California

LILIA MONZO

University of California at Los Angeles

JOHANNA SHAPIRO

University of California at Irvine

JUAN GOMEZ

JAN BLACHER

University of California at Riverside

ABSTRACT: *This study used several focus groups to examine culturally based variation in attitudes, beliefs, and meanings of transition. Sixteen Latina mothers of young adults with disabilities participated in the study, recruited from an agency serving low-income, predominantly Spanish-speaking communities. Data analysis identified five primary themes: (a) basic life skills and social adaptation, (b) the importance of the family and home rather than individualism and independence, (c) the importance of the mother's role and expertise in decision making, (d) access to information; and (e) dangers of the outside world. The overarching theme was a view of transition as home-centered, sheltered adaptation as opposed to a model emphasizing independent productivity. The findings and the implications for future research and practice are discussed.*

Transition is an important part of the service system for students with developmental disabilities, a period during which young adults prepare for life beyond mandatory schooling (Blacher, 2001). During this time, decisions about living arrangements, further schooling, work placements, and the like

must be made primarily by the young adult (whenever possible) with the input of teachers, school personnel, service agency representatives, and parents (Kramer & Blacher, 2001).

Despite the key role of transition as both a construct and a process in the service delivery system, little is known about culturally based variations in attitudes, beliefs, and meanings of

transition for those involved. The present article begins to address this gap by providing a qualitative look at these areas from a group of Latina mothers of young adults with disabilities. Before reporting on the study, we provide a brief review of the concept of transition, and then discuss the role of cultural issues and why a cultural perspective is needed in the field.

THE CONCEPT OF TRANSITION

Transition reflects a service delivery focus on the pursuit of a productive, independent life (Rusch & Menchetti, 1988), including domains such as career choices, future social relationships, and living arrangements (Halpern, 1985). Beginning no later than age 14, each student now must have included in the individualized education program (IEP) a statement of the transition services that he or she needs in order to prepare for such postschool outcomes as employment, postsecondary education, adult services, independent living, and community participation (IDEA Amendments, 1997), although the actual process of transition can take place anytime from ages 14 to about 26.

AMBIGUITY, VARIATION, AND ALTERNATIVE VIEWS OF TRANSITION

Transition planning for young adults with disabilities can be more complex and ambiguous than that involving nondisabled persons, the most obvious difference being that transition decisions for nondisabled young adults are generally informal processes that occur within the locus of the family, and interaction with larger social systems (i.e., colleges, workplace) are to some extent voluntary. Nondisabled adolescents and teenagers gradually assume responsibilities and roles that result in increasing independence, and transition to adulthood is often marked by specific life events (going away to college, marriage, employment, moving from home). Although there may be variance, the general expectation is that a nondisabled young adult will become independent from the family at some point. Successful transition of the young adult with disabilities, however, is less clearly delineated and is predicated on the notion of life-

long support from family members, advocates, and/or agencies.

Transition for both persons with and without disabilities may be further complicated when cultural differences are involved (Blacher, 2001; Harry, Rueda, & Kalyampur, 1999; Lehmann & Roberto, 1996). For example, there is some evidence of cultural variation regarding "normal" childrearing or family practices for young adults without disabilities (Gallimore & Goldenberg, 2001; Magaña, 1999). In the special education literature, studies have shown variation in the meaning attached to disability (Blacher, 2001; Geenen, Powers, & Lopez-Vasquez, 2001; Harry, 1992a; Kalyampur & Harry, 1999) and to service delivery systems and the values embedded in them (Chavira, Lopez, Blacher, & Shapiro, 2000; Gomez & Shapiro, 2000) from different cultural perspectives. This work suggests caution in assuming the universality of values such as development, life outcomes, family structures and roles, parenting, independence, and individual achievement apart from one's nuclear family that may be implied in discussions of the concepts of normalization and least restrictive environment.

An alternative view is that the notion of transition can be seen as a social construction, highly symbolic in ways that go beyond the more mundane issues related to living arrangements and economic support. A culturally relative framework allows for variance in the underlying values that define what is normal and desirable as well as in the timing and degree of expected developmental changes.

A small body of work investigated the issue of transition in different cultural settings. Shapiro, Monzo, Rueda, Gomez, and Blacher (2004) described Latina mothers' perspectives related to the service delivery system surrounding transition. Primary concerns of these mothers included (a) poor communication with service providers, (b) low effort on the part of service providers, (c) negative attitudes of professionals toward client-children, and (d) negative treatment of parents by professionals. Although these mothers adopted a role of advocacy for their offspring, they did so in an alienated rather than a collaborative fashion because of lack of trust and disillusionment with how they and their children were treated. The study also documented the mothers'

belief in their role as central to the well-being of their children.

In another study, Harry (1998) followed seven culturally diverse families over a 4-year period, focusing on socialization patterns and social pathways of family members with a disability. Harry documented the strong sense of family and family decision making that cut across all of the participants. Expectations for children's development were closely tied to cultural assumptions about child rearing, family structure, and sibling responsibility. In addition, families' values were discrepant with values espoused in the field in general and in legislation in particular around areas such as personal choice, friendships, independence, and equality of opportunity. Although there was important variation among even the small number of families studied, Harry suggested that a "normal life" is a highly culturally influenced concept about which the families held differing expectations compared with those for other children without a disability.

It is unclear if the variance in values and practices among different groups described in these studies reflect economic, class, cultural, or other influences, but it is clear that views about the underlying values vary. On the one hand, seemingly universal assumptions and meanings regarding transition may be inappropriate when applied to diverse populations (Geenen et al., 2001; Meier-Kronick, 1993). On the other hand, there is danger in making inferences about individuals based on group membership. This issue is briefly addressed in the following section.

A NOTE ON CULTURAL MODELS, CULTURAL PRACTICES, AND CONTEXT

Gallimore and Goldenberg (2001) described *cultural models* as shared mental schema or normative understandings of how the world works, or ought to work, including what is valued and ideal, what settings should be enacted and avoided, who should participate, the rules of interaction, and the purpose of interactions. With respect to services for persons with developmental disabilities and their families, such models would

help define what is normal, expected, and appropriate.

One problem with discussions of culturally based beliefs and values is that often these are treated as stable, context-free, and pervasive among all members of a group. This presumed homogeneity fails to capture the dynamic nature of cultural beliefs and also fails to account for the variability often seen among members of the same cultural, ethnic, or racial group. However, Gallimore and Goldenberg (2001) noted that even though a group may appear homogenous and may widely share similar cultural models, these shared models can produce varying *cultural practices* among members of the same group, depending on features of specific social contexts, and these need to be differentiated. In the present study, we focused on common themes in Latina mothers' cultural models related to transition, but did not focus on cultural practices.

WHY ARE CULTURAL DIFFERENCES IMPORTANT?

A major reason for focusing on variations in assumptions, beliefs, and values is the increasingly diverse population as well as different outcomes among groups. The recent *Twenty-fourth Annual Report to Congress on the Implementation of the Individuals With Disabilities Education Act* (U.S. Department of Education, 2002) documented that the racial, cultural, and language backgrounds of students in America's schools have changed dramatically in recent decades. This is also reflected in the population of students with disabilities. The report noted that Hispanic students exhibited the largest increase, being half again as large in 2001 as in 1987 (14% vs. 9%). There was more than a fourfold increase in the percentage of students with disabilities who did not use primarily English at home (3% to 14%). Thus, growing numbers of students with disabilities face the challenges of communicating in two languages and accommodating two cultures, in addition to the challenges posed by their disabilities (U.S. Department of Education).

Failure of the service delivery system to account for this diversity in values and beliefs may make transition more difficult for some groups than for others. The National Longitudinal Study (Blackorby & Wagner, 1996), for example, re-

vealed that African American and Latino youth with disabilities had greater difficulty than European American youth with disabilities finding employment, and when they did work, earned significantly less than European American workers. Given these circumstances, it is important to more closely examine variation among different groups in order to refine the concept of transition and the service delivery system that reflects it. Work to date suggests that culturally relevant issues need to be documented and considered in order to facilitate the widest possible access to services for all members of society.

PURPOSE OF THE STUDY

Although work such as Harry's (1992a, 1998) examined developmental disability and service delivery issues from a cross-cultural perspective, little work has been done on culturally based differences specifically on transition for students with disabilities and their families. In order to add to what is known about this issue, we conducted a qualitative study of Latina mothers' views of transition and transition-related issues and compared these views with the explicit and implicit assumptions in the current regulations and practices involved around the concept of transition and transition planning. We explored a wide range of participants' views of transition and the transition planning process. We used these responses to identify common themes in the cultural models regarding transition-related issues of these Latina mothers.

METHOD

PARTICIPANTS

Although the 16 mothers who participated in our study were Latina mothers of young adults with developmental disabilities, and all lived in low-income predominantly Latino and Chicano communities of the East Los Angeles area, it is important to note the diversity of the participants who fell under this umbrella. Two came originally from Ecuador, 1 from Peru, and the remainder had emigrated from Mexico except for 2 who were born in the United States. The immigrant

mothers had lived in the United States for some time (between 8 and 40 years). Spanish was the primary language of 14 of the mothers. The other 2 spoke Spanish but seemed more comfortable speaking in English. Their ages ranged between 35 and 68. Their education levels varied. Seven had completed 1 to 6 years of education, 3 had completed 7 to 8 years of education, 2 had completed some high school, and 4 had some higher education either at the college level or at a trade school. Ten of the 16 mothers were married. Only 4 out of the 16 mothers were employed. Although Latinos are often seen as a homogenous group, there is often significant variability in country of origin, length of time in the United States, language proficiency and use, education, employment, marital status, and so forth. Thus, the variability among this group was not unexpected.

Work to date suggests that culturally relevant issues need to be documented and considered in order to facilitate the widest possible access to services for all members of society.

In age, their sons and daughters ranged between 14 and 31 years. All 16 young adults had severe disabilities and lived at home with their parent(s). Based on maternal reports, 7 were diagnosed with Down syndrome, 4 with autism, 3 with mental retardation (unspecified), 1 with pachygyria (a genetic disorder), and one with microcephaly. Nine had not yet completed their transition programs, whereas 7 had already transitioned, or exited, out of the school system.

We recruited participants through a non-profit community organization that provides support services to families of children with developmental disabilities. A staff member from the agency who had close interaction with the families served assisted in recruiting Latino parents who had children between 14 and 25 years of age with severe developmental disabilities, our initial target range based on our estimate of the approximate age range during which issues of transition would be salient. However, in order to

secure a sample with the number and types of young adults we sought (students with severe disabilities), we went slightly above the initial target age range. Participants received a \$40 honorarium immediately following their participation. Although no emphasis was placed on which parent was sought in our recruitment efforts (or perhaps because of this), we secured participation only from mothers.

FOCUS GROUP AS A METHOD OF RESEARCH

Focus groups involve informal discussion among a small group of participants who are asked to express their viewpoints or opinions on a particular topic about which they have special expertise or life experience. The objective is to explore experiences and beliefs rather than to reach consensus (Carney et al., 1998). They can be particularly useful in encouraging participants to provide candid, complete, and in-depth responses. Because responses from participants are shared or discussed, more diverse, and often more nuanced, opinions are gathered than what would be possible to obtain with an individual interview.

DATA PROTOCOL AND COLLECTION

The research team used a question protocol (Shapiro et al., 2004), translated by a Latina member of the team who was familiar with the local community, and this translation was then reviewed by other bilingual team members. Themes addressed included participants' definitions of transition, involvement with social service agencies, their rights to support services, the impact of transition on the young adolescent with severe disabilities and his or her family, differences and similarities of transition between children with severe disabilities and their nondisabled siblings, and out-of-home placement.

A familiar and comfortable setting was sought for the meetings, and a back room in a local church was identified by the community agency that assisted in recruiting participants. Focus groups were conducted approximately 2 weeks apart. Each one was about 3 hr in duration.

Three focus groups were conducted. The first group included 4 participants and was conducted bilingually, with much code switching (Zentella, 1997) and repetition in both languages.

Only 2 participants of the 6 recruited arrived for the second focus group, held entirely in Spanish. The third focus group had 10 participants, a larger than optimal size that was related to over-recruitment based on the experience with the second group. A bilingual Latina doctoral student with experience conducting qualitative interviews and focus groups with other Latinas/os from similar communities facilitated all three focus groups. A second bilingual Latino researcher, who was also present at all of the focus groups, took careful field notes while the discussion was taking place.

Focus group discussions were primarily informal in nature. Following recommendations by other cross-cultural researchers to adopt a recursive, open-ended approach in interviewing (Blakely, 1982) and an innovative interviewing style with elements of "*la platica*" (social conversation; Moll, Rueda, Reza, Herrera, & Vasquez, 1976), the interviewer willingly engaged in discussions with participants of issues not directly related to the research project and proceeded at the pace and response sequence of the respondents. All focus groups were audio recorded and later transcribed and translated verbatim. The bilingual members of the research team reviewed all transcripts for accuracy.

DATA ANALYSIS

Data analysis took place simultaneously with data collection. Debriefing sessions were held after each focus group session to begin to identify categories and themes in the data. In addition, written transcripts were reviewed several times by all investigators.

Transcript data were compared both within and across groups. Initial ideas, themes, and categories were first identified using open coding (Vaughn, Schumm, & Sinagub, 1996), then fractured and recoded using axial coding to make connections between categories and subcategories that reflected more generalized themes and patterns. Finally, themes were used to form a grounded theory (selective coding) that clarified concepts and allowed for interpretations and conclusions (Gilgun, Daly, & Handel, 1992). The goal of analysis was to identify patterns, make comparisons, and contrast one set of data with another in order to explore the cultural models

and issues surrounding transition for these Latina mothers.

MAJOR THEMES

Data analysis identified five primary themes surrounding transition for these participants: (a) basic life skills and social adaptation, (b) the importance of the family and home rather than individualism and independence, (c) the importance of the mother's role and expertise in decision making, (d) access to information, and (e) dangers of the outside world. The overarching theme that emerged from the data was mothers' view of transition as *home-centered, sheltered adaptation* as opposed to a model emphasizing independent productivity. Each of these issues, as well as the overarching construct, is discussed in more detail in the following section.

A FOCUS ON BASIC LIFE SKILLS AND SOCIAL ADAPTATION

The emphasis of the analysis was on exploring participants' definitions and associations with the term *transition*. A consistent theme was Latina mothers' salient concerns for their sons' and daughters' continued development of basic life skills. Although work placements and employment considerations were addressed, they were primarily seen as a vehicle for continuing school placement and further development of basic life skills. These mothers placed a high priority on the development of life skills such as bathing, fixing light meals, and so forth. However, the development of these skills was not discussed in terms of a final goal of independent living, but rather in terms of increased independence with respect to hygiene and personal self-help in the context of existing living and care arrangements. As the following (translated) example suggests, mothers were clear that they were primarily concerned that their young adults with disabilities become more self-sufficient in terms of their personal needs. Olga, "I want her to wash her own plates, make her bed, take a bath, daily things that she can do by herself. I would like her to learn how to cook, just small things."

A related subtheme for these mothers was a strong preoccupation regarding their young

adult's social development, especially ways to handle relationships with the opposite sex, sexual curiosity or feelings, and aspects of developing friendships. For example, one mother explained the frustration and ambivalence she felt about her son's growing sexual curiosity and her fear that he might not realize that this is a private matter; she worried how he might handle this curiosity at his work placement where she was not present. Another mother expressed concern over her daughter's growing romantic feelings for her brother-in-law. She explained that she had tried many times explaining to her that her brother-in-law was her sister's husband and that he cared for her like a sister. However, the daughter did not seem to understand the differences in feelings or how to act appropriately with the brother-in-law. A problem perceived by the mothers was that their young adults were increasingly showing interest in romance and in social activities such as going to parties, and they discussed a need for support in handling these issues.

INDEPENDENCE AND THE ROLE OF THE FAMILY AND HOME

For the mothers in the focus groups, the marker for independence and the time for their children to make their own decisions was *not* when they left school and entered young adulthood, but rather when they left home, a developmental milestone primarily associated with marriage. Until such time, mothers felt that their children were not free to make their own decisions merely because they might be adults under the law. The notion of having one's young adult go off on his or her own was not part of the mindset of these mothers, irrespective of whether a developmental disability was involved, and this value was often referenced to their own experiences growing up, as illustrated in the following (translated):

Olga: Never. I have never said that to my daughter. I told her, "When your own daughters are grown, never tell them to leave, because that is very Anglicized." And among Latino families, no, on the contrary, my father used to tell me, "Why do you want to be going out all the time? You have your house here."

The home was seen as the appropriate residential setting for the young adult with develop-

mental disabilities, but it was also seen as a safe haven in the event of something happening to the mother. The care of their young adults with disabilities was viewed as the mother's own responsibility while she was alive, and the responsibility of another family member if she was no longer able to provide care. Several mothers noted plans for siblings to take over the young adult's care when the mother died, but some were unsure about their nondisabled child's willingness or ability to care for the young adult. In any case, independent living as an option for the young adult with disabilities was discussed and considered a ludicrous and inappropriate concept by most of these mothers.

THE MOTHER'S ROLE AND EXPERTISE IN DECIDING TRANSITION ISSUES

Another dominant theme was the mothers' strong belief that no one would be able to care for their children with disabilities better than they did themselves. These mothers perceived themselves as more knowledgeable about their children and better able to make decisions about work placement and living arrangements for their children than the professionals involved. The mothers' decision-making role also superseded any decision making on the part of the young adult with disabilities. Although mothers felt it was important

These mothers perceived themselves as more knowledgeable about their children and better able to make decisions about work placement and living arrangements for their children than the professionals involved.

to ask their young adults their opinion and to take their desires and preferences into consideration, mothers also felt that they—as parents—should make all final decisions about transition planning.

It is interesting to note, however, that despite their determination to maintain control of the transition decision-making process, these mothers felt that their children were often much

more capable than professionals realized. Indeed, mothers often referred to their children with disabilities as “normal” or “very intelligent.” For example, consider the way this mother, Reina, described her son to us (translated from Spanish):

He is a very handsome young man and he is attending the Easter Seals and his functional level is basically a moderate mental retardation, very intelligent. He has the functions, that he is a normal young man. He has been diagnosed like a boy of 6 and 8 years old, but that diagnosis was done in 1987, but I see that my boy is more mature, that is, that he doesn't represent that age.

This belief in their offspring's competence was often at odds with how professionals perceived these young adults—as only disabled, without particular strengths, and incapable of performing any meaningful life tasks, as illustrated in the following (translated):

Luisa: I sometimes think that the personnel working with our children, I think they don't treat our young children as serious.

Rosa: Yeah, I agree with you.

Luisa: Even when you hear them having a conversation like they're talking to a baby and I think that's hard, you know.

However, the important point to understand is that mothers wanted professionals to see the strengths and capacities of their children not so they could be autonomous decision makers, but so they would be treated with respect and caring. Mothers saw themselves as the appropriate decision makers and regularly complained that their expertise and experience were considered less valuable than the academic knowledge of professionals such as teachers and agency workers. For example, one mother recounted a story in which her son became very excited and aggressive with his sister (who herself was studying in the area of special education) during a family outing. The mother explained to her daughter that she knew how to manage her son best, and how to minimize his tendency toward aggression (example translated from Spanish): “Look Tere, I think that here I have something [more knowledge] over you

because I know how and I tell you that when you see him nervous don't say anything to him."

The mother explained, however, that the daughter had not heeded her warning, discounting her insights, and had attempted to rush her brother thereby making him nervous in a large crowd; indeed, her son had reacted aggressively just as she feared.

ACCESS TO INFORMATION

As previously mentioned briefly, many mothers discussed needing additional information about transition issues, particularly with respect to services. We did not learn of any mothers who had been able to find services that adequately dealt with their many concerns. Some of the mothers suggested that parent groups would be especially beneficial, where they could learn from each other, discuss their particular situations, and get advice from other mothers.

The desire for access to information was based on both a desire to receive useful services relevant to their children's needs, but also on a mistrust of service providers' motives. In one focus group, for example, a point of discussion was that professionals sometimes encouraged the young adult to adopt the professionals' position regarding independent living, even though it went against the mother's beliefs.

A significant concern of these mothers was the poor communication between themselves and caseworkers, teachers, and other professionals, which was due in part to the fact that many felt that they lacked information regarding transition planning and service options. Some mothers believed that parent involvement in the transition decision-making process was only perfunctory and that many professionals preferred mothers to be *less* informed and less involved. As evidence for this, some mothers noted that parents lacked viable sources of information, in Spanish, regarding work placements and other transition services. Some mothers indicated that the professionals they dealt with objected to being questioned regarding the details of the services they were providing, and that they resented mothers making suggestions about the quality and type of transition services desired. The sense was that increased information would lead to empowerment in dealing with professional service providers, even

though it might also have negative consequences for interactions with those same providers. As one mother articulated (untranslated):

When a parent starts getting too smart and really learning the system then you little by little become a persona non grata wherever you go because you do know the system, you do know your rights and they like resent it.

An important obstacle to parents making informed choices regarding transition seemed to be the lack of availability of information in Spanish. Yet mothers pointed out that even having materials translated into Spanish would not remove all barriers, as many immigrant mothers may not have sufficient reading skills to comprehend the often complex language used.

DANGERS OF THE OUTSIDE WORLD

A final theme was a generalized fear of the dangers of the world outside of the family setting, in particular the perceived lack of adequate supervision in work placements. Prior to the transition from school to work, most young adults were housed within the school facility; posthigh school work placements often involved activities that

[A] point of discussion was that professionals sometimes encouraged the young adult to adopt the professional's position regarding independent living, even though it went against the mother's beliefs.

took them out into the community. Some mothers felt that there was significantly less supervision in these work placements than there had been at school.

Related to this concern was the possibility of discrimination against young adults with disabilities, because work placements often involved having the person with disabilities become integrated into the community with nondisabled persons, where the same levels of protection and sensitivity offered at school were not always observed. A number of stories of discrimination

were shared among the mothers. They were especially concerned about their young adult's feelings, commenting that the young adults were aware of being discriminated against. The following excerpt (untranslated) provides an insight into these concerns:

Carolina: Yoli was accused one day at Pavilions of stealing because we were grocery shopping and I told Yoli, "Go and get that tuna." So she went and, you know, she looked and these kids, they look, and they look kind of suspicious. And she always has a handbag. So, anyway, she brought the cans and put them in. And the boy that works there in the grocery part came and said that the guard had been watching her and for me to look in her bag because he felt that she had stolen something and put it in there. Well to look into her bag was quite a problem because she got offended. We showed the guy that there was nothing in there.

Luisa: They didn't let me in to Marie Callender's because Jennifer's wheelchair was taking up too much room.

Thus, for the mothers in this study, the community involvement aspects of transition often represented negative and dangerous experiences because of both insufficient supervision (compared to earlier school settings) and discrimination against persons with disabilities.

DISCUSSION

There is an implied model in the laws and policies regarding transition that assumes that the problem-solving process is collaborative, that the partners in the collaboration are well-informed and knowledgeable, and that the values and goals of all parties correspond. In addition, there is an assumption that all partners in transition value normative timelines and goals focused on independent functioning and productivity. In previously reported research (Magaña, 1999; Shapiro et al., 2004), it has been suggested that these assumptions do not hold up well, particularly from the perspective of Latina mothers. This study provides further evidence that there may be multiple perspectives on transition, some of which may conflict with the views of transition implied in

various official policies and definitions. In the present study, as noted earlier, the view of transition reflected was based on a model of *home-centered, sheltered adaptation* as opposed to a model emphasizing independent productivity. In discussing these findings of the study, we first focus on the specific themes that emerged as well as two more general issues. These two issues concern the homogeneity in the views expressed by participants and the issue of whether the present findings are universal or culturally specific.

BASIC SKILLS AND SOCIAL ADAPTATION VERSUS PRODUCTIVE WORK

In the United States, in general, much emphasis is placed on what one does with respect to work and how one's work relates to one's identity. However, these mothers did not view employment, now or in the future, as a major aspiration for their young adults with disabilities. We found that, contrary to a common focus in the transition planning on vocational experiences and work placements, the absence of discussion about future employment in our focus groups suggested that these mothers did not consider work placements or employment as particularly pertinent issues. Rather, when employment settings were discussed, it was with reference to an extension of school and an opportunity to continue basic skills training, or else as a source of apprehension because of the perception of various dangers.

THE IMPORTANCE OF THE FAMILY AND HOME VERSUS INDIVIDUALISM AND INDEPENDENCE

Another aspect of transition planning typically includes an emphasis on the individual student's concerns and desires. This is based on the assumption of shared decision making and on the view that high school students should be involved in decision making about their own transition. However, these mothers did not speak often of issues reflecting independence or individualism, nor did they view these concepts as synonymous with young adulthood. Mothers' expectations, even for their nondisabled offspring, did not favor independent living arrangements without clearly sanctioned transition points such as marriage. Given these mothers' sentiments regarding their children without disabilities, independent or

group living arrangements for their children with disabilities (an option often introduced and recommended by professionals in the course of transition planning), was inconsistent with their beliefs and values.

THE MOTHER'S ROLE AND EXPERTISE IN DECISION MAKING VERSUS THE PROFESSIONAL'S

Previous research (Shapiro et al., 2004) suggested a strong sense of dissatisfaction of Latina mothers with respect to the service delivery system and with service providers. Variance in the values and understandings of transition decision making may be partially at the root of this dissatisfaction. In these focus groups, mothers clearly felt that they had greater expertise than did professional service providers about their individual children. Moreover, the emphasis on collaborative decision making and the importance of the views of the young adult with disabilities were not as much a priority as they may have been for service providers or as implied in the law. At the same time, lack of confidence in service providers also led mothers to believe that professionals underestimated the competence of their offspring, which resulted in disrespectful and uncaring attitudes and behavior toward the children.

ACCESS TO INFORMATION AS A SAFEGUARD VERSUS A PLANNING TOOL

The desire for more information on the part of mothers was tempered by a mistrust of service providers and the service delivery system in general. Although access to information was seen as a tool to pave the way for increased services, it was also seen as a form of protection from motives of service providers that might not be in the family's best interests. This is consistent with the notion of "alienated advocacy" (Shapiro et al, 2004) in which adversarial interactions between families and service providers are based on mothers' perceptions of unfriendliness, aloofness, and lack of sympathy on the part of professionals. While on the surface it might appear that lack of access to information might be addressed by more creative outreach efforts on the part of service providers, the underlying dynamics of the concern suggest that a more fundamental issue is at stake. This is consistent with earlier work that discussed profes-

sional service providers' attitudes that devalue or dismiss parental insights and observations (Kalyanpur, 1998).

DANGERS OF THE OUTSIDE WORLD

Transition policies often seem to assume that productive involvement in the community is a critical outcome of successful transition. Yet for these mothers, successful transition was not indexed by increased interactions with the larger society. In fact, the community involvement aspects of transition often represented negative and dangerous experiences because of both perceived insufficient supervision (compared to earlier school settings) and possible discrimination against persons with disabilities. An interesting issue, not explored here, is the extent to which these beliefs and attitudes reflect these mothers' own experiences and interactions with the larger society and social institutions.

Whereas transition is often seen as a unitary phenomenon, there may be multiple dimensions or levels of transition (Harry, 1992a, 1998). As suggested earlier, for example, transition marks changes for the individual with a severe disability on at least the following dimensions: (a) social/personal development (moving from being cared for toward independence), (b) roles within the family (from child/adolescent to adult), and (c) role within the service delivery system (from student to productive worker).

A fundamental issue underlying these dimensions of transition is the target of intervention and how it changes over time. Although the service delivery system might emphasize a family focus for young children with a disability, the implied expectation is that the target would increasingly focus on the young adult with developmental disabilities. This is consistent with the goals of increased independence, productive and supportive employment, and integration into the larger community. However, this same shift did not appear in the discussions of these mothers. Rather, the focus appeared to be a consistent emphasis on the home/family, similar to what others have found (Harry, 1998). A strong view expressed was that the well-being of the family member with the disability is not separable from that of the family, and that independence is marked by shifts in specific roles of family mem-

bers (such as marriage). Although transition may have represented a structural shift for the young adult with a disability (e.g., from school to work), for these mothers and families, it did not necessarily represent a role shift for the mother or young adult. With the increasing diversity represented in the special education system, it will be important to examine more systematically and in different contexts the most appropriate ways to assure the best outcomes and to achieve the “posture of reciprocity” advocated by Kalyanpur and Harry (1999, p. 498).

DISSENTING VOICES IN THE DATA

There was a strong pattern of uniformity in the responses of the participants and the themes generated through the analysis. Although this may seem unusual given the variance in the backgrounds of the mothers, it is consistent with the cultural models versus cultural practices distinction described earlier in this article. Despite individual, educational, linguistic, and immigration-related differences, these mothers shared a general cultural model that influenced their thinking in similar directions on broad issues such as individual autonomy versus family, productivity versus self-care, and so forth. Whereas significant differences might not be expected at this general level of cultural models, significant differences among participants would be expected at the level of specific cultural practices. That is, had this study investigated what these families actually do within their individual local ecological settings, considerable variance might be anticipated. Economic necessity or family circumstances such as death or divorce, for example, might lead to cultural practices that may appear to conflict with the underlying cultural models. We argue that inferences about cultural practices should not be made based solely on information about general cultural models. This is an important limitation in the present study that needs to be highlighted. Although we are confident that we were able to elicit key aspects of these mothers’ cultural models, we did not investigate cultural practices. Thus, even though there was a great deal of consensus about features of the cultural models, because specific cultural practices were not investigated directly, there may be significant variance in individual practices in different social

contexts. Future studies should focus on both aspects.

UNIVERSAL VERSUS CULTURALLY SPECIFIC PATTERNS

The question might be raised as to whether the themes identified in this study are unique to the Latina mothers who participated in the focus groups, or whether they express more universal issues. To some extent, it is indisputable that most parents, regardless of cultural background, and regardless of their children’s abilities or disabilities, want their children to acquire basic self-care skills,

We argue that inferences about cultural practices should not be made based solely on information about general cultural models.

develop social relations, and find productive (and even meaningful) work. Most parents value the family, but also allow a certain level of individualism and independence in family members. Likewise, most mothers feel that they have important knowledge about their own children, although they are usually willing to listen to the perspectives of others with special expertise, such as teachers, physicians, or pastors. Parents also regard information about how systems work, and options available to their children, as useful in planning their children’s futures as well as in protecting their children’s interests. Finally, there are probably few parents who do not appreciate that the world is a place of some danger, but nevertheless recognize that their children must somehow venture into it at some point. Therefore, we argue that differences are a matter of emphasis, rather than absolutes.

What was striking to us as researchers was the lack of a shared perspective between these mothers and the system designed to help them and their children. (It should be recalled that we did not attempt to assess the personal values and beliefs of system caseworkers, many of whom were Latinos themselves. We did form the impression that regardless of variability in personal beliefs, in their professional roles as caseworkers and

teachers they tended to represent the assumptions and priorities of the system that employed them.) In every instance concerning the major themes we identified, the orientation of the mothers and of the service delivery system appeared to be at odds. Where the system stressed productivity, and put less attention on social development, to mothers productivity was a pleasant, but rather irrelevant afterthought; their real worries focused on the need to encourage socially appropriate interactions in their children. Where the system repeatedly tried to view the young adult child as an autonomous individual, mothers found this approach a disturbing violation of their view of the child as embedded in the family. Whereas to the system, privileging of professional expertise seems correct, mothers felt their personal knowledge of their children was devalued and ignored. The system tends to regard information as value-neutral, but to the mothers it was not simply a technical tool, but a protection and at times even a weapon that could be used to ward off those who did not appear to have the best interest of their child at heart. Although many recognize the sometimes considerable risks encountered in the larger society, most generally assume that all people must take their proper place in that society. The mothers of this study reacted quite negatively to this assumption, and challenged its relevance and veracity.

We believe that families coming out of the dominant cultural model that helped to shape the present service delivery system for persons with disabilities will be more likely to place emphasis on similar values. Although generalizing is always risky when speaking about particular cultural groups, we speculate that these families will tend to recognize, be comfortable, and agree with values of productivity, independence, expert knowledge, information as a tool, and assimilation into the larger society. Although we would expect significant variation in terms of how these particular themes of the dominant cultural model are translated into cultural practices for specific subgroups or specific families, we also suggest that participating in a shared model creates a greater sense of safety in families, therefore less alienation and less resistance. For the mothers in our study, the lack of a shared model appeared to lead to confusion, misunderstanding, and isolation.

CONCLUSION

Care should be exercised in generalizing these results to parents of young adults with disabilities in general or even to other Latina mothers. We cannot claim to have identified a representative sample of the population of Latino families who receive services. The sample was recruited from a community agency and was drawn from those who were known to the agency, willing to participate, and able to attend the sessions. Focus groups, by design, are not representative, nor should any attempt be made to generalize from them.

In addition, the perspective of service providers, fathers, and other family members are not represented here, and may provide different ways of understanding the issues discussed. A more systematic exploration of the dynamics of the transition planning process with both service providers and the entire family would be useful. However, taken together with earlier work with similar populations (Harry, 1992b; Kalyanpur & Harry, 1999; Zetlin, Padron, & Wilson, 1996), it is reasonable to hypothesize that problems continue to exist in Latina mothers' perceptions of, and satisfaction with, the service delivery system in special education in general and in terms of transition in particular. As other investigators have noted in a point of great relevance to the present study, "How one defines 'successful adulthood,' the end goal of transition planning, is determined by culture-specific values and expectations about many important issues, such as work, community integration, role expectations, and social functioning" (Geenen et al., 2001, p. 266). The issues of values, beliefs, and cultural models represented in the diverse clientele served by the special education system remain an important area of investigation as a means of assuring equal access and meaningful collaboration for all young adults and their families. Finally, there are currently no lifespan perspective studies that investigate these issues. The existing studies, taken as a group, present an interesting cross-sectional view, but it would be valuable to investigate the development and change over time in mother's beliefs, values, and perspectives as a result of ongoing contact with the service delivery system.

REFERENCES

- Blacher, J. (2001). Transition to adulthood: Mental retardation, families, and culture. *American Journal on Mental Retardation, 106*(2), 173-188.
- Blackorby, J., & Wagner, M. (1996). Longitudinal postschool outcomes for youth with disabilities: Findings from the National Longitudinal Transition Study. *Exceptional Children, 62*, 399-413.
- Blakely, M. (1982, October). Southeast Asian refugee parent survey. Paper presented at the conference of the Oregon Educational Research Association, Newport.
- Carney, P. A., Rhodes, L. A., Eliasson, S., Badger, L. W., Rand, E. H., Neiswender, C., et al. (1998). Variations in approaching the diagnosis of depression: A guided focus group study. *Journal of Family Practice, 46*, 73-82.
- Chavira, V., Lopez, S. R., Blacher, J., & Shapiro, J. (2000). Latina mothers' attributions, emotions, and reactions to the problem behaviors of their children with developmental disabilities. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 41*, 245-252.
- Gallimore, R., & Goldenberg, C. (2001). Analyzing cultural models and settings to connect minority achievement and school improvement research. *Educational Psychologist, 36*(1), 45-56.
- Geenen, S., Powers, L. E., & Lopez-Vasquez, A. (2001). Multicultural aspects of parent involvement in transition planning. *Exceptional Children, 67*, 265-282.
- Gilgun, J. G., Daly, K., & Handel, G. (Eds.). (1992). *Qualitative methods in family research*. Newbury Park, CA: Sage.
- Gomez, J., & Shapiro, J. (2000, June). *Implementing transition for Latino young adults with mental retardation: Mothers' perspectives*. Poster session presented at the meeting of the American Association on Mental Retardation, Denver, CO.
- Halpern, A. (1985). Transition: A look at foundations. *Exceptional Children, 51*, 479-486.
- Harry, B. (1992a). *Cultural diversity, families, and the special education system: Communication and empowerment*. New York: Teachers College Press.
- Harry, B. (1992b). An ethnographic study of cross-cultural communication with Puerto Rican-American families in the special education system. *American Educational Research Journal, 29*, 471-494.
- Harry, B. (1998). Parental visions of "una vida normal/a normal life": Cultural variations on a theme. In L. H. Meyer, H. Park, M. Grenot-Scheyer, I. S. Schwartz, & B. Harry (Eds.), *Making friends: The influences of culture and development* (pp. 47-62). Baltimore: Paul H. Brookes.
- Harry, B., Rueda, R., & Kalyampur, M. (1999). Cultural reciprocity in sociocultural perspective: Adapting the normalization principle for family collaboration. *Exceptional Children, 66*, 123-136.
- Individuals With Disabilities Education Act, Pub. L. No. 101-476, 20 U.S.C. 33 (1990). (Available from the Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402.)
- Individuals With Disabilities Education Act Amendments. (1997). Pub. L. No. 105-17, 20 U.S.C. 1400 *et seq.*
- Kalyampur, M. (1998). The challenge of cultural blindness: Implications for family-focused service delivery. *Journal of Child & Family Studies, 7*, 317-332.
- Kalyampur, M., & Harry, B. (1999). *Culture in special education: Building reciprocal family-professional relationships*. Baltimore: Paul H. Brookes.
- Kramer, B. R., & Blacher, J. (2001). Transition for young adults with severe mental retardation: School preparation, parent expectations, and family involvement. *Mental Retardation, 39*, 423-435.
- Lehmann, J. P., & Roberto, K. A. (1996). Comparison of factors influencing mothers' perceptions about the futures of their adolescent children with and without disabilities. *Mental Retardation, 34*, 27-38.
- Magaña, S. (1999). Puerto Rican families caring for an adult with mental retardation: Role of familism. *American Journal on Mental Retardation, 104*, 466-482.
- Meier-Kronick, N. (1993). Culture-specific variables that may affect employment outcomes for Mexican American youth with disabilities. In T. Dais, N. Meier-Kronick, P. Luft, & F. F. Rusch (Eds.), *Selected readings in transition: Cultural differences, chronic illness, and job matching* (Vol. 2, pp. 22-40). Champaign: University of Illinois, Transition Research Institute. (ERIC Document Reproduction Service No. 372 518)
- Moll, L. C., Rueda, R. S., Reza, R., Herrera, J., & Vasquez, L. P. (1976). Mental health services in East Los Angeles: An urban community case study. In M. R. Miranda (Ed.), *Psychotherapy with the Spanish-speaking: Issues in research and delivery* (Spanish Speaking Mental Health Research Center Monograph No. 3, pp. 21-34) Los Angeles: University of California.
- Rusch, F., & Menchetti, B. (1988). Transition in the 1990's: A reply to Knowlton and Clark. *Exceptional Children, 54*, 363-365.
- Shapiro, J., Monzo, L., Rueda, R., Gomez, J., & Blacher, J. (2004). Alienated advocacy: The perspective of Latina mothers of young adults with developmental

disabilities on service systems. *Mental Retardation*, 42(1), 37-54.

U.S. Department of Education. (2002). *Twenty-fourth Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act*. Washington, DC: U.S. Government Printing Office.

Vaughn, S., Schumm, J. S., & Sinagub, J. (1996). *Focus group interviews in education and psychology*. Thousand Oaks, CA: Sage.

Zentella, A. C. (1997). *Growing up bilingual*. Malden, MA: Blackwell.

Zetlin, A., Padron, M., & Wilson, S. (1996). The experience of five Latin American families with the special education system. *Education and Training in Mental Retardation and Developmental Disabilities*, 31, 22-28.

SHAPIRO, Professor, Department of Family Medicine and Director, Program in Medical Humanities and Arts, University of California at Irvine, College of Medicine. **JUAN GOMEZ**, Doctoral Student, Graduate School of Education, Families Project; and **JAN BLACHER**, Professor and Faculty Chair, Graduate School of Education, University of California at Riverside.

Requests for reprints should be sent to: Dr. Jan Blacher, Graduate School of Education, University of California, Riverside, CA 92521.

This research was supported by grant number HD21320 from the National Institute of Child Health and Human Development (Dr. Jan Blacher, Principal Investigator). The authors would like to thank participating parents from the University of California, Riverside *Families Project*, and *Fiesta Educativa*. We would also like to acknowledge the assistance of *Fiesta Educativa* in recruiting families for this study.

Manuscript received April 2004; revision accepted October 2004.

ABOUT THE AUTHORS

ROBERT RUEDA (CEC Chapter #188), Professor, Rossier School of Education, University of Southern California, Los Angeles. **LILIA MONZO**, Postdoctoral Fellow, Graduate School of Education and Information Sciences, University of California at Los Angeles. **JOHANNA**

Collaborative Information Centers

A consortium of six federally-funded national information and dissemination centers that collect and provide information on disability-related issues.

- The National Center on Low-Incidence Disabilities
<http://www.ncld.unco.edu>
- NICHCY, the National Dissemination Center for Children with Disabilities
<http://www.nichcy.org>
- Project Forum
<http://www.nasdse.org> (click "Projects" then "Project Forum")
- DB-LINK, The National Information Clearinghouse on Children Who Are Deaf-Blind
<http://www.dblink.org>
- Laurent Clerc National Deaf Education Center - Info to Go
<http://clerccenter.gallaudet.edu/InfoToGo>
- The George Washington University HEATH Resource Center, National Clearinghouse on Postsecondary Education for Individuals with Disabilities
<http://www.heath.gwu.edu>