A JOURNAL OF POLICY, PRACTICES, AND PERSPECTIVES 02.04

Mental Retardation

VOL. 42 NO. 1

AAMR | PUBLICATION OF THE AMERICAN ASSOCIATION ON MENTAL RETARDATION

BY JOHANNA SHAPIRO, LILIA D. MONZO, ROBERT RUEDA, AND OTHERS

Perspectives of Latina Mothers on Service Systems

Regardless of whatever good intentions and efforts may exist among teachers and caseworkers of Latino young adults with developmental disabilities, results of this study suggest serious concerns held by mothers of these young adults regarding the educational and service systems. Above all, our research suggests a cultural "disconnect," at least for these mothers, which probably cannot be solved by simply providing informational pamphlets in Spanish, scheduling additional didactic presentations, or providing better referrals. *(Article begins on page 37)*

Articles

Available online at www.aamr.org

MENTAL RETARDATION VOLUME 42, NUMBER 1: 37–54 | FEBRUARY 2004

Alienated Advocacy: Perspectives of Latina Mothers of Young Adults With Developmental Disabilities on Service Systems

Johanna Shapiro, Lilia D. Monzó, Robert Rueda, Juan A. Gomez, and Jan Blacher

Abstract

Although collaborative partnership between parents and professionals is a cornerstone of the special education and service systems, this relationship exists more as an ideal, especially when low-income, culturally diverse families are involved. Through three focus groups, we examined the beliefs of 16 low-income Latina mothers of young adults with developmental disabilities about their relationships with the educational and service delivery systems. Primary concerns identified were (a) poor communication, (b) low effort in providing services, (c) negative attitudes of professionals toward the client–children, (d) negative treatment of parents by professionals, and (e) the mother's role as central to the well-being of her child. Mothers tended to adopt a posture of *alienated advocacy* in relation to their child's educational and service needs.

The overarching goal of the special education and related service delivery systems is to conform to a cluster of "best practices" in serving children with developmental disabilities and their families. These practices include, as a key component, meaningful parental participation (Schopler & Mesibov, 2000; Westling & Fox, 1995). Parental involvement in all aspects of service and educational planning was incorporated into P.L. 94–142 (Federal Register, 1977) and again into the Individuals With Disabilities Education Act (P.L. 101–476). These laws are intended to enable parents to function as full and equal partners in all education and transition planning processes (Turnbull & Turnbull, 1998). In practice, however, the ability to fulfill this intention of meaningful parental involvement is complicated by multiple social and cultural factors.

Skrtic (1995, 1991) observed that the prevailing social discourse of the special education field, rooted in assumptions of the medical model and professional expertise, privileges school and service delivery authorities over parents, especially those from different cultural and socioeconomic backgrounds. Despite rhetoric of collaboration and participation, the insularity of professional practice, the power and authority of professionals, and the assumed superiority of professional expertise inevitably disadvantage parents (Kalyanpur & Harry, 1999; Skrtic, 1995). Professionals are trained to adopt the view that they, rather than parents, are the ones best able to establish right and proper practices for their clients (Kalyanpur, 1998). The insights and knowledge of parents, especially those from oppressed or disenfranchised groups, are necessarily devalued or ignored in the professional world (Sanchez, 1999; Turnbull & Turnbull, 1997). As a result, many minority families come to view the educational system as a bureaucracy controlled by educated, monolingual, monocultural individuals whom they have no power to question (Nicolau & Ramos, 1990). These families often have not acquired the cultural capital—that is, the deep understanding of implicit and/or explicit values, knowledge, practices, and effective ways of acting on those values, knowledge, and practices that is rewarded in a given sociocultural context (Apple & Beane, 1995; Bourdieu & Champagne, 1999; Portes, 1998)—with respect to institutions in the United States to understand the purposes of educational/service delivery systems and how they work. Thus, their ability to successfully negotiate within the special education culture is severely restricted. Harry (1992a) concluded that tensions regarding unequal power and authority underlie most parent–professional encounters.

The concept of parent participation is based on theoretical assumptions about the availability of equal opportunities, the ability to assert individual rights, and the capacity to exercise free choice (Kalyanpur, Harry, & Skrtic, 2000; Spindler, Spindler, Trueba, & Williams, 1990). Yet, in contemporary American society these assumptions are only imperfectly manifest at best and may not be familiar to or accepted by all parents. It follows that those already in power will be the ones to define the terms under which parental involvement occurs (Bennett, 1988; Correa, 1992; Harry, 1992a; Kalyanpur & Harry, 1999).

Professionals have produced participatory models that are primarily medical and legal in origin and, therefore, are often bewildering to parents with different sociocultural orientations. For example, the medicalized language framing special education has had the unintended effect of defining children with disabilities solely in terms of deficits (Biklen, 1988; Mercer, 1973). This dichotomous perspective alienates parents, who are more likely to simultaneously view their children as *normal* and *disabled* (Harry, 1998; Mardiros, 1989)). To be forced to work within a framework that so persistently focuses on their child's inadequacies is at once alienating and a contradiction of parents' daily experience. As another example, the legalistic framework outlining parental advocacy, which is intended to provide protection to clients, in fact is likely to promote adversarial relationships between parents and professionals (Harry, 1992a). The language of rights that defines the parameters of parent–professional interactions implies defending what one has and fighting for that to which one is entitled, positions also unfamiliar and uncomfortable for many parents (Kalyanpur, Harry, & Skrtic, 2000).

In early studies of intervention programs, researchers generally report high satisfaction among Latino parents (Lynch & Stein, 1987; McNaughton, 1994). However, in her review of participation by minority parents in the special education process, Harry (1992a) reported (a) lower levels of participation; (b) lower levels of awareness of special education procedures, rights, and services; (c) an expressed sense of isolation and helplessness; (d) logistical problems, such as child-care, transportation, and difficulties related to stressful life circumstances; (e) low self-confidence in interactions with professionals; and (f) culturally based reluctance to question authority of school officials. To these issues, other investigators added minority parents' fear of retaliation by professionals if they voiced concerns regarding their children's educational plan or services (Bennett, 1988; Leon, 1996).

In an in-depth, qualitative study of five Latino families, Zetlin, Padron, and Wilson (1996) noted parental feelings of mistrust for teachers and other school personnel and perceptions of school personnel as unfriendly or indifferent. More recently, Bailey, Skinner, Rodriguez, Gut, and Correa (1999) similarly found in a sample of Latino families that their degree of satisfaction with the educational and service delivery systems was only moderate and that 17% were either mostly or entirely dissatisfied. Even more disturbing was the finding that greater awareness of programs and greater use of services were both associated with *greater* parental dissatisfaction. The most dissatisfied parents in Bailey et al.'s study mentioned teachers whom they felt were not committed, complained of feeling discriminated against by certain agencies because of their ethnic background, and were upset at not being able to find the services or information they needed. The authors concluded that variables related to the nature of the service agency or program were more relevant to parental satisfaction than were family and/or child variables.

In initial scholarly interpretations, investigators attributed ethnic parents' dissatisfaction with the special education system to concrete factors, such as language differences, inconvenient scheduling, time required to attend meetings, and transportation and child-care constraints (Turnbull & Turnbull, 1990). However, Ware (1994) hypothesized that poor implementation and logistical constraints were *outcomes*, not causes, of low parental participation and emerged from profound and pervasive cultural differences. Harry (1992a, 1992b) and Kalyanpur (Kalyanpur, 1998; Kalyanpur & Harry, 1999), drawing on the work of Hall (1977), have used a social constructivist analysis to show how the philosophical assumptions that determine the dominant social discourse of different cultures can produce very different models for effective parent–professional relationships.

Hall (1977) argued that high context cultures, such as those of many Latin American countries, emphasize interpersonal networking and relationships based on personal knowledge, trust, warmth, and caring. This cultural attitude stands in contrast to low context cultures, such as that of the United

States, which highlight positivist criteria of objectivity and rationality in professional dealings. In Harry's (1992b) study, mothers preferred Puerto Rican schools in which teachers wielded unquestioned authority but also provided safety and love compared to the more technical, less affectionate approach they encountered in the United States. Other scholars have also commented on the importance of a professional interaction style with Latino parents that is personalized and characterized by a close and caring relationship (Cazden, Carrasco, Maldonado-Guzman, & Erikson, 1985). Confronted by professionals whose demeanor appears officious and indifferent, parents from high context cultures often feel mistrustful and ineffectual, although they may continue to "present the face of *respeto* (respect)" to authorities (Bennett, 1988, p. 150). The clash between the directive, quick fix, problem-solving American approach (McGowan, 1988) and the more indirect approach based on personal relationship may lead to many parent–professional misunderstandings.

Drawing on both the early mental health literature of the 1970s and more recent special education literature regarding provision of services to Spanish-speaking and Spanish-surnamed individuals, we can identify certain general themes that have been recommended, although much less frequently adopted, to promote effective parent–professional relationships. These include treating family members and their cultural patterns with respect and cultivating interpersonal relations based on trust between families and representatives of formal institutions or organizations—*personalismo* (Padilla, Ruiz, & Alvarez, 1976). Harry (1992b) also made several suggestions for developing successful special education programs to serve culturally diverse populations. She recommended forming personalized, individual relationships with families rather than large-group structured interactions as well as the use of parent advocates as mediators between parents and professionals from different cultural and SES backgrounds. Other authors confirmed the importance of being more person- than task-centered (Kalyanpur & Rao, 1991).

In a case study of community schools serving Latino and Southeast Asian children, Zetlin, Ramos, and Chee (2001) concluded that staff should function in a warm, caring, and respectful manner, not dissimilar to an extended family. An ideal parent–professional relationship with high context families should avoid formalism, proceed at an unhurried pace, incorporate humor, and foster in service providers an attitude that is nonjudgmental, supportive, warm, friendly, and caring (Salend & Taylor, 1993; Summers et al., 1990). Blue-Banning, Turnbull, and Pereira (2000) recently reported that Latino parents value teamwork, cooperation, partnership, shared responsibility, a trusted group of people to use as a sounding-board, flexibility in the planning process that is tailored to the individual needs of the child, and collaboration and support. It is critical to recognize that, without exception, all of these recommendations, although focused on specific attitudes and behaviors, emerge from a social constructivist analysis in which professional privilege is challenged; multiple, coexisting, and equally valuable worldviews are acknowledged; and the cultural capital of both parents and professionals are respected.

Our purpose in the present study was to examine the beliefs and perceptions of Latino parents of young adults with severe developmental disabilities around the issue of transition. *Transition planning* involves the preparation of young adults with disabilities for leaving high school and entering the world beyond (Kramer & Blacher, 2001). With few exceptions (Geenen, Powers, & Lopez-Vasquez, 2001), little is known about how the transition process affects Latino parents, especially those whose sons or daughters are homogeneous with respect to level of supports and services that they require. The necessity of a participatory, collaborative partnership between parents and professionals at this developmental phase is particularly crucial because of the inherent complexities in the transition process for their young adults and because of the psychological vulnerability experienced by some of these mothers (Blacher, Lopez, Shapiro, & Fusco, 1997). Unfortunately, in real-world situations, parents often do not feel welcome or encouraged by professionals to participate in these educational and service planning processes (Westling, 1996).

A series of three focus groups was conducted toward this end. As in most qualitative research, numerous themes emerged specifically pertinent to the topic under investigation (i.e., the process of transition). In addition, other themes were also expressed concerning issues not entirely anticipated, including those discussed below regarding mothers' perceptions of their interactions with social service agencies and educational systems. Here, we expand upon the latter theme and report the beliefs and insights of low-income Latina mothers about the delivery of educational and developmental disability services.

Method

Recruitment

We recruited participants through a nonprofit organization that provided support services to minority families of children with developmental disabilities. Following suggestions for research methods appropriate to Latino communities (Magaña, 2000), we emphasized interpersonal interactions with trusted go-betweens in the recruitment process. A staff member from the agency who generally interacts with the families seeking support was informed about the purpose of the study and asked to contact families who met study criteria. Specifically, we wanted to recruit Latino parents who had children with moderate to severe developmental disabilities who were between 14 and 25 years of age because we believed that this was the approximate age range during which these young adults and their parents might begin anticipating, learning about, and/or dealing with issues of transition.

Participants were told that they would receive a $40 honorarium immediately upon completion of participation in the focus group. We attempted to use a purposive sampling technique (i.e., selecting participants because of their knowledge of and experience with the topic under discussion [Brotherson, 1994]). However, sampling was also influenced by factors of convenience and accessibility. No emphasis was placed on which parent was sought in our recruitment efforts, but (perhaps because of this), only mothers agreed to participate.

Because these mothers were recruited by a community service organization staff person, they were individuals who were informed enough to have access to such services and also to have made an impression on recruiters sufficient to consider them for enrollment in the study. It is also possible that more confident, assertive mothers were more likely to volunteer to participate. However, our sense was that the extent to which these mothers were knowledgeable and actively engaged in negotiating services for their children fell along a continuum of proficiency. Some mothers seemed quite knowledgeable and belonged to multiple support groups, whereas others had little knowledge of how to negotiate within the educational and service systems and did not know that they had options with respect to the services their children received.

Participants

Participants were 16 Latina mothers of young adults with developmental disabilities. They ranged in age between 35 and 68 years. All lived in low-income, predominantly Latino and Chicano communities of the East Los Angeles area. Fourteen of the mothers were immigrants but had lived in this country for some time (between 8 and 40 years). Eleven of the women were born in Mexico; 2, in Ecuador; 1, in Peru; and 2, in the United States The primary language of 14 mothers was Spanish. Although 4 of the 16 mothers had some higher education either at the college level or at a trade school, the largest number (7) had only completed between 1 to 6 years of education. Three had completed 7 to 8, and 2 had completed some high school. Ten of the 16 mothers were married. Only 4 of them were employed. It is important to note that although many similarities exist among Latinos in the United States, there is also significant variability among them on various demographic and cultural dimensions. Some of this variability is reflected in the differences in country of origin, length of time in the United States, language preference and proficiency, and educational level reported in this study.

The sons and daughters of these women ranged in age between 14 and 31 years. All 16 young adults had moderate to severe disabilities and lived at home with their parent(s). According to maternal report, 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; 7 had already transitioned out of the school system.

The 16 young adults had all either recently participated or were currently participating in special education programs, and all were also receiving services through the local Regional Center. This means that each young adult was assigned a particular service-coordinator with whom the family (usually the mother according to reports) negotiated the child's needs regarding his or her particular disability (e.g., SSI benefits, work and/or continuing education placements, and/or living placements). These young adults and their families (especially mothers) also were in direct communication with Regional Center supervisory staff as well as with individuals directly responsible for services, such as doctors, speech and physical therapists, and/or work supervisors. However, the conclusion of the research team was that the professionals referred to in the focus groups were primarily either teachers or service coordinators.

Somewhat ironically in light of recommendations to meld professional roles and functions embodied in the school-linked services integration movement (Skrtic & Sailor, 1996), these focus group participants did not seem to make categorical distinctions between the educational system (i.e., special education classes), the service delivery system (i.e., Regional Center), and the professionals associated with each. They used the terms *case worker, social worker, and teacher* somewhat interchangeably. Wherever possible, we have tried to make clear which type of professional respondents intended to reference.

Rationale for the Selection of Focus Group Methodology

We used a focus group methodology to explore attitudes and beliefs of parents about educational and transitional services for their young adult child with developmental disabilities. Conducting focus groups involves the facilitation of informal discussion among a small group of people who are selected according to a predetermined set of criteria. Each focus group is comprised of individuals who only participate in that one group, and, generally, 3 to 5 such groups are conducted, with the goal of achieving theoretical saturation (Morgan, 1998). Focus group members are asked to express their viewpoints or opinions on a particular topic about which they have special expertise or life experience. Qualitative research methods in general, and focus groups in particular, are a useful way of revealing underlying value structures (Harry, 1992a) and learning about people's attitudes, beliefs, and behaviors in relation to sensitive issues. The objective of focus groups is to explore experiences and beliefs rather than to reach consensus (Carney et al., 1998). They are particularly valuable in encouraging participants to provide candid, complete, and in-depth responses. The dialogue generated in focus groups tends to create a synergistic effect, thus allowing a wider range of insight and information than is possible with an individual interview (Stewart & Shamdasani, 1990). Focus groups are also particularly helpful in eliciting opinions from individuals who have a history of limited societal power and influence (Morgan, 1993).

Data Source and Collection Procedures

In this study, a question route was designed and revised four times by a research team that included three bilingual Latino team members. After its completion, it was translated by a Latina member of the team and reviewed by the other two Latinos. We paid particular attention to how the questions might be interpreted by participants given cultural differences. The major themes covered in the question route included folk definitions of *transition*, involvement with social service agencies, rights to support services, the impact of transition on the young adolescent with severe disabilities and on the family, differences and similarities of transition between children with severe disabilities and their nondisabled siblings, and out-of-home placement (see Appendix A).

The questions were kept open-ended to allow diverse opinions to emerge, and participants were encouraged to discuss other related areas of concern that arose during conversations. In addition, we were concerned that some mothers might feel awkward about expressing divergent or unpopular opinions in the presence of the other mothers. We addressed this concern at the outset of each focus group by telling participants how important it was to understand the diverse experiences and beliefs represented in the group and that therefore disagreement was not only acceptable, but common and natural. In addition, after a seemingly popular viewpoint had been discussed, we would specifically ask whether anyone had any different experiences or thoughts they wanted to express.

The focus groups were held in the back room of a church in East Los Angeles, a location often used for meetings by the organization that aided us in recruitment. Because of this association, the location was familiar to and comfortable for focus group participants. Focus group meetings were conducted approximately 2 weeks apart; each was about 3 hours in duration.

A bilingual Latina doctoral student (the second author), who had experience conducting qualitative interviews and focus groups with other Latinos or people from similar communities, facilitated all three focus groups. A second bilingual Latino researcher (the fourth author) was also present at all meetings of the focus groups and took careful field notes while the discussions were taking place.

Building rapport was particularly important to focus group facilitators. We were aware that limited contact between participants and researchers (participants had not met the researchers prior to holding the focus groups) would perhaps inhibit group members from sharing personal experiences and being candid regarding their beliefs. This concern was a primary reason for having a bilingual, bicultural Latina (the second author, an immigrant from Cuba but raised in the Los Angeles area in a low-income immigrant community similar to that of the focus group participants) conduct the interviews. One of her strengths as a researcher is her knowledge of and ability to connect to this particular community. She brought to this study the conviction that everyone has important knowledge and experience to share, and she conveyed this belief through careful attention to participants as they shared their thoughts during the focus groups. The second facilitator, a young, soft-spoken man who did not seem intimidating to a group of older women, was also bilingual and bicultural. He was born in the United States and raised in a neighboring community in the Los Angeles area. Although he participated at times in the conversation, he was primarily responsible for taking notes. Both facilitators interacted with participants with *cariño* (a culturally appropriate interactional style among Latinos that conveys caring), smiling gently, listening respectfully and attentively, and offering snacks. Because of their familiarity with Latino contexts, both facilitators felt comfortable among the women, which we believe helped to put participants at ease.

Focus groups were conducted around a table, large enough for everyone to sit comfortably but small enough to make the interactions seem personal. The two facilitators sat mixed among the participants as members of the group. Although it was evident that they were the researchers, we believe this minimizing of distinctions between interviewers and mothers also increased the comfort level. Although facilitators employed a question route, the focus groups were conducted as discussions. The second author asked initial questions and moved to others when the conversation flagged. She looked directly at participants as they spoke and mentally kept track of which questions were covered as the conversation moved in whatever direction that participants took it. She sometimes paused and asked for clarification, indicating that she did not understand, showing her own lack of experience with certain subject matter and her interest in participants' comments. Focus group discussions were informal in nature, as evidenced by the fact that mid-way through the exchange, mothers began to look at each other to respond to comments and questions without waiting for the researcher's prompts.

Facilitator interruptions of the conversational flow to continue with another question were minimal and occurred only when necessary to address all questions in the time allotted. The second author was aware that, generally speaking, interrupting speakers would be inappropriate. Thus, necessary interruptions took place at appropriate pauses in the discussion. The interviewer accompanied each interruption with a gentle smile and a tilt of the head that indicated to the speaker that the interviewer wished to comment, thus softening the interruption into a silent negotiation between the two parties. At the end of each focus group, participants seemed to have enjoyed their involvement. Some asked whether they could have more regular group meetings. Others encouraged facilitators to call them with any follow-up questions.

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 plática* (social conversation) (Moll, Rueda, Reza, Herrera, & Vasquez, 1976), the interviewer willingly engaged in discussions with participants about issues not directly related to the research project and proceeded at the pace and response sequence of the respondents. For example, although the emphasis of the question route was on issues of transition, and no questions specifically asked participants to evaluate or comment on educational and service systems generally, in fact mothers made numerous observations about these topics.

Three focus groups were conducted, each with a different set of participants. The first focus group included 4 individuals. It was originally to have been conducted in English but upon beginning the focus group, it became clear that some of the individuals present preferred to speak in Spanish. For example, one mother explained that she needed to use Spanish if she was going to speak about her daughter. Another mother, however, preferred English. Thus, this focus group was conducted bilingually, with much code switching (Zentella, 1997) and repetition in both languages. Overall, it seemed that participants followed the conversation well and were able to participate.

Only 2 of the 6 scheduled participants arrived for the second focus group. This group was significantly different from the other two in that the 2 mothers spoke at length (approximately 20 minutes) about their own personal experiences and perceptions, almost in narrative form. This differed from the other two focus groups in which each person kept their introductory and subsequent comments at a level more appropriate to the give and take quality of a conversation. In the second group, the interactional dynamics were such that the older woman began to offer advice to the younger one, who in turn asked for guidance from the older one. However, we were careful to ensure that the question route was followed after the initial narration by taking advantage of pauses or making eye contact with participants that allowed us to subtly interject our questions. This focus group was held entirely in Spanish.

Ten mothers participated in the third focus group. We had over-recruited participants because of our experience with the second group. This was a difficult focus group to conduct, and it was clear that the more vocal women in the group dominated the conversation. The interviewer attempted to encourage the less vocal women to share their thoughts by interjecting at appropriate pauses and asking (without singling anyone out) if anyone else wanted to share experiences or had other thoughts. The major questions discussed in the other two focus groups were addressed and lively discussions did take place.

All focus groups were audiorecorded, using two separate tape recorders. The tapes were later transcribed and translated verbatim by a bilingual professional translator. The bilingual Latino researchers reviewed all transcripts for accuracy. The two researchers who were present in the focus groups (the second and fourth authors) were also able to fill in gaps in the transcripts that were difficult to hear on tape. Quotes provided to illustrate our findings are included exactly as they occurred in the original communication. Because the second and third focus groups used Spanish only, all quotes from participants in these groups appear first in Spanish and then are presented in the English translation to facilitate readers' understanding. Because the first focus group was conducted bilingually, participants spoke either in Spanish or in English. Those who were bilingual sometimes spoke in English and at other times in Spanish. Any quotes presented in English only were spoken in English.

Data Analysis

As in other kinds of qualitative research, data collection and data analysis proceeded simultaneously and recursively throughout the study (Marshall & Rossman, 1995). After each focus group, facilitators held a debriefing session in which they identified initial categories and themes that were emerging from the data, checked for consensus, explored disagreements, and discussed modifications or additions to the question route. Because a single reviewer may not be able to extract all of the important information from a session, all transcripts were reviewed several times by all investigators. Extensive summaries of the focus group interviews were also made and exchanged for comment and revision.

We utilized a content analysis approach that was initially descriptive, then interpretive. The unit of analysis was primarily each focus group, rather than individual comments, but data were compared both within group and across groups. In analyzing the data, we paid attention to disconfirming evidence and outliers. We also took into account elements of frequency, extensiveness, and intensity in the analysis. Ideas or phenomena were first identified and flagged to generate a list of internally consistent, discrete categories (open coding), then fractured and reassembled (axial coding) by making connections among categories and subcategories to reflect emerging themes and patterns (Vaughn, Schumm, & Sinagub, 1996). Finally, categories were integrated 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.

We established the trustworthiness of the conclusions by establishing that our findings were generally consistent across multiple informants (i.e., three different focus groups). That is, although there were some differing opinions expressed about particular service coordinators or teachers, in general there was consensus concerning participants' overall reactions with respect to *typical* dealings with *most* representatives of the educational and service delivery systems. Trustworthiness was also established through the use of multiple researchers and analysts, coding checks of categories, and verbatim transcripts that provided thick descriptions. In addition, we reviewed our interpretation of findings and the conclusions we drew with 2 participants in accordance with member-checking procedures. These 2 participants were selected for this purpose based on their contributions to the focus group discussions. One participant was chosen because she was less vocal than others, and we wished to understand whether her experiences were represented in the discussion. Another participant was chosen because at times she expressed differing views, and we sought to explore these differences further.

Member checking was completed during independent informal visits by the two researchers who conducted the focus groups. During member checking, they presented the study interpretations and asked participants whether they agreed that these conclusions fairly represented the group discussion and whether they personally agreed or disagreed. In this process, respondents were explicitly told that we wanted to learn from them, that we sought to provide a good representation of the group members' different experiences and beliefs, and that it was important to capture variability if it existed. This checking procedure confirmed our interpretations of the overall tone and major points discussed among group members. It also confirmed that the major findings were representative of the participants' views. The mother who was an outlier had expressed satisfaction with services received and good rapport with workers. However, during member checking, we found that both the delivery of services and rapport with her service coordinator had previously been unsatisfactory and had improved only upon her making her concerns known. Also, although she did not have an overall negative view of the special education and delivery systems as did the majority of mothers, as part of the member checking she did recount examples of similar negative experiences to those expressed by the other mothers in the focus groups.

Findings

As a result of the data analysis, we identified five primary issues for these participants: (a) poor communication with professionals in educational and service systems, (b) lack of effort by professionals providing services, (c) negative attitudes of professionals toward the children whom they were supposed to serve, (d) negative treatment of parents by professionals, and (e) mothers' role in relation to the educational and service systems. The main theoretical construct that emerged from the data was mothers' adoption of a posture of *alienated advocacy* in response to perceived disrespect and lack of caring within the educational system. Each of these issues, as well as the overarching construct, is discussed in more detail below.

Poor Communication and Lack of Information

Mothers generally felt that communication was poor between parents and caseworkers/teachers. Many of them talked at length about having the feeling that programs, resources, and possibilities existed "out there" but that they were not given sufficient information to be able to access them or utilize them appropriately. Mothers repeatedly commented that information relevant to their child's future does not reach them or falls through the cracks. The following comment shows one mother's concern and frustration over this issue:

> *Group 2, Esperanza:* Uno piensa siempre que está uno muy bien informado y la verdad de las cosas es que no. Uno cree estar informado. Me llega mucho información y ya cuando tiene uno el problema encima se da uno cuenta de la falta de información que uno tiene. (One always thinks that one is very well informed and the truth of the matter is that no. One believes to be informed. A lot of information comes to me and when the problem is on top of you, you come to realize the lack of information that you have.)

A number of mothers also felt that informational pamphlets or other forms of written material were not adequate, especially given that many of these were not offered in Spanish. One mother pointed out that even those materials that were in Spanish were not accessible to parents who did not have significant schooling and familiarity with conventional literacy forms. She added that even when parents read such literature, different families often interpreted it differently. Whatever educational and informational efforts were being made by Regional Centers or school staff, mothers felt a lack of knowledge about their options.

Lack of Effort: Doing the Minimum and Withholding

Mothers complained about lack of coordination and follow-through, pointing to little or no continuity and consistency in their child's learning programs. They also remarked on the system's inability and/or unwillingness to provide promised services.

Group 1, Rachel: Por ejemplo, le preguntan qué es lo que uno quiere para el hijo o qué es lo que él pide o quiere, le hacen la lista a uno aunque, desafortunadamente, yo se que no van a cumplir. Entonces no estoy muy contenta con el programa ahorita. (For example, they ask what you want for your son or what it is that he asks for or wants, they make the list for you even though, unfortunately, I know that they will not comply with it. So right now I am not very happy with the program right now.)

This mother said bluntly that her child's program was a waste of time because of inconsistent follow-through between school and home, and across schools, regarding her child's functional goals and objectives.

Often these deficiencies in coordination and follow-up were attributed to an attitude among professionals of just getting by, doing only the minimum necessary. Mothers suggested that programs did not want to provide resources or information to children and would only do so under pressure from parents. Some mothers felt this lack of coordination was a sign schools did not take their own programs seriously: "They're [educational and training programs] just something to do with kids." In the view of several mothers, this attitude among professionals resulted in actual denial or withholding of services that were legally and morally due the child. Some mothers shared specific situations in which they had been put off by coordinators.

Group 3, Marta: No pedí ayuda para ella [hija] y como no eramos [residentes] legales también, pues, yo decía, "Estos servicios no se los van a dar a ella." Verdad? Para mí eso estaba cerrado. Entonces pagué mucho dinero, digo, no se le hace a uno por que cualquier sacrificio es nada para sus hijos, verdad? Pero habiendo el servicio pero no te dicen y si no los piden no los dan. (I did not ask for help for her [daughter] and since we were not legal [residents] also. Well, I thought to myself, "These services are not going to be given to her." Right? For me that was closed. I paid a lot of money, I mean, I don't feel it because any sacrifice is nothing for your children, right? But having the service available but they don't tell you and if you don't ask for them, they're not given.)

Negative Attitudes Toward Children

There was significant concern that the very people entrusted with the well-being of the children, namely service coordinators and teachers, did not care about them. As one mother diplomatically expressed it, "Some social workers want to help and some do not." Other manifestations of this lack of caring included workers who did not know the child on a personal basis, were not familiar with the child's file, or who treated their clients like John and Jane Does.

Group 1, Paloma: They don't know, they don't learn your child. They're just doing it by what they call hearsay. They're just reading it; they don't know you, they don't know your child.

There was a pervasive belief that service coordinators could not really be helpful unless they had intimate personal knowledge of the child and family, yet it was precisely this sort of knowledge that, in the opinion of many mothers, was lacking. A further aspect of this was the perception that service coordinators did not think the children were important and did not take their problems seriously enough.

Another source of potential conflict among service coordinators, teachers, and parents was the perception that the professionals tended to pathologize their children, while not recognizing their unique strengths and abilities, something the mothers considered essential for establishing a good relationship. There was the implication that service coordinators and teachers did not appreciate the strong points of the children and perhaps did not even see them as fully human. By contrast, although mothers often referred to their child as "mentally retarded" and "slow," many also referred to them as "normal," "healthy," "smart," or "with their own intelligence." This ability to see their child as simultaneously disabled and nondisabled was a balance the professionals seemed to miss. The omission was extremely troubling to parents, who believed that professionals who negatively labeled the children without recognizing their unique strengths and abilities could not truly help their child in any meaningful way.

Negative Treatment of Parents

Mothers also complained about their own treatment at the hands of professionals when they sought to secure the services that they believed they had a right to receive. They complained that service professionals were often rude, rushed them through meetings, and treated them as if they were wasting their time. Mothers talked of workers who never had time to talk to parents or even got angry with them. "Parents are treated like dirt," "like they're asking for hand-outs or begging," and "are not even shown common courtesy."

Group 1, Olivia: It aggravates me when I see somebody, people that are working in the social services for our kids and they look at you. . . like you're asking for a hand-out.

Paloma: You're begging.

Olivia: You're begging. How dare you? What right? They treat you like dirt.

Paloma: Es que hay veces, todo el tiempo, se enojan. Nunca tienen tiempo. "Tenemos muchos clientes." Es verdad. Tienen muchos clientes para poco empleados. Pero hay maneras de expresarse y no ser tan rudos con las personas. (It's that there are times, all the time, they get angry. They never have time. "We have many clients." It's true. They have many clients for few employees. But there are ways in which to express oneself and not be so coarse with the people.)

Some mothers were concerned that it was difficult to establish rapport and form relationships with service coordinators because of the high turnover. Others commented that even when they tried to get to know the service coordinators, there was often a lack of trust and confidence. A significant cause of distress was the sense that teachers and service coordinators routinely ignored parental expertise about their children. Mothers persistently commented that because they knew their children better than anyone else, they also understood their needs better than did professionals. Others confirmed they were treated as though they did not know anything.

Mothers who seemed more knowledgeable about the system complained that although the concept of parent participation was outwardly promoted, professionals did not value their input and sometimes even resented parental contributions as inferior to their own expert knowledge, which they seemed to perceive as more valid.

Group 1, Olivia: I think it's ironic that the school system and the Regional Center system and the whole system that has to do with our children want, especially now, want a bigger participation of parents, and they always tell you even in school "We want the parent to participate; we want you to come; we want you to do this." But when a parent starts getting too smart and really learning the system then you little by little become like a persona *non grata* wherever you go because you do know the system, you do know your rights, and like they resent it.

Furthermore, issues of ethnicity were not lost on the participants. In their view, primarily English-dominant professionals frequently perceived these mothers as less knowledgeable and expected them to be less involved compared to non-Hispanic white parents. One woman recounted how she was treated by professionals who had a narrow conception of Latino parents' knowledge, interest, and involvement in the services their children receive.

Group 1, Linda: Something went wrong. I went and talked to the head, the person in charge, and she says, "Well, you're just one of those Mexican people who has a brain, who is educated. Not very many are. . . " They rather deal with someone where they can take advantage of that person and do whatever they want to do with that person, and it's really sad, it's really sad.

Mothers' Role in Relation to the Special Education System

Mothers tended to see themselves as the antithesis of all the system's flaws. They understood their core maternal responsibility and duty as dedicating themselves to their child's education and development. This is evident in the following excerpt taken from one of the focus groups.

Group 3, Estrella: Solo le pido a Dios que me de, pues, vida y salud para ayudarle y seguir adelante con él [hijo]. (I only ask God that He give me, well, life and health in order that I may help him [son] and continue ahead with him.)

Marta: Trabajé muy duro con ella [hija]. (I worked very hard with her [daughter].)

Ana: Es que la madre es la maestra del niño. Los maestros en las escuelas. (It's that the mother is the child's teacher. The teachers in the schools.)

Marta: Ellos no son los maestros. (They're not the teachers.)

Ana: Claro que no. (Of course not.)

According to this perspective, the mother understands and appreciates her child as only a mother can. As a result, she willingly does everything possible to move her child forward developmentally, intellectually, and socially.

Alienated Advocacy

Given these views of the educational and service delivery systems' shortcomings and the appropriate maternal role required, it is understandable that most of the respondents felt compelled to adopt a position of advocacy for their child. However, because of the lack of trust and disillusionment with how they and their child were treated, this advocacy was not expressed in their functioning as part of a team within the system. Rather, it tended to take the form of confrontational, alienated, adversarial interactions designed to ensure that their child was not neglected or ignored.

On the one hand, mothers recognized that the American educational and service systems for children and young adults with developmental disabilities were necessary and desirable. Indeed, many of these families had come to the United States specifically to seek better health care and educational opportunities for their child with developmental disabilities. Yet, once in this country, mothers experienced these systems as cold, uncaring, and disrespectful. Further, in the opinion of many mothers, the systems did not recognize and made no allowances for the personal expertise about their own child that, in their worldview, formed the core of their maternal role. Given these perceptions, mothers felt they had no choice but to develop a stance of alienated advocacy to protect the rights and needs of their child. The operation of this construct undoubtedly led to interactions with service systems personnel that at times were both adversarial and conflictual. However, our analysis suggests that the underlying phenomenon was not so much a desire for or belief in confrontation as it was the subjective experience of estrangement, disaffection, unfriendliness, aloofness, and lack of sympathy that drove these mothers' behavior.

Group 3, Rina: Yo pienso que en este caso nosotros somos abogados de nuestros hijos. Debemos buscar lo mejor para ellos. A ellos no les interesan nuestro hijos. Nosotros somos los interesados y nosotros somos abogados también. (I think that in this case we are advocates for our children. We need to find the best for them. . . They [school personnel] are not interested in our children. We are the ones interested and we're advocates too.)

At times, the mothers saw themselves as the only ones standing between their children and an impersonal, indifferent bureaucracy.

Group 3, Rina: Le voy a decir una cosa, señora. Ellos tienen como 300 clientes. El que le de más lata, esa es a la que le van hacer caso. Yo a mi trabajadora le digo el lunes, "Okay, mi hija necesita estos servicios, el vienes quiero la respuesta." Y el viernes yo le hablo por teléfono, "Qué pasó?" "O, no, que mire," "Ok, el lunes arreglamos esto." Así se hacen las cosas. . . Es que a ellos no les interesan nuestros hijos. (I'm going to tell you something, mam. They have around 300 clients. The one who complains most is the one who they're going to give their attention to. I tell my worker on Monday, "Okay, my daughter needs these services, I want the response on Friday." And I call her on Friday by telephone, "What happened?" "Oh, but look," 'Okay, on Monday we'll fix this.' That's how these things are done. . . . It's that our children do not interest them.)

Marta: Tienen que exigir, exigir sus derechos como quien dice. Por que ellos le dan la larga y si usted no habla. (You have to demand, demand your rights, as one would say. They'll give you the run around and if you don't speak up.)

Ana: Mire, yo he peliado por el niño mio, yo he peliado mucho y yo me he metido donde quiera me metido. (Look, I have fought for my son, I have fought a lot and I have entered wherever I have entered.)

Some mothers remarked on the additional challenge of effectively advocating for their children because of their own perceptions regarding Latina women's difficulty with questioning authority or speaking up. Others commented on the inhibitory influence of not speaking English or lacking formal education. They commented that they often felt afraid or did not know how to go about asking for help. Nevertheless, they felt they had no choice but to "fight" for their children. One woman compared herself to a dog fighting for its young.

Group 3, Ana: Por qué [los trabajadores de la escuela] se quedan callados? Por qué? Por que no preguntamos sobre los programas que hay para defender nuestros hijos. Yo le voy a decir una cosa y a ustedes se los digo. Yo soy como las perras, yo sí. (Why do they [school personnel] keep quiet? Why? Because we don't ask about the programs that are out there for defending our kids. I'm going to tell you something and to you I will say it, I'm like the female dogs, I am [meaning that you fight when you need to]).

Apparently Inconsistent Perspectives

Several mothers acknowledged that, over the years, they had encountered professionals who were helpful and that, in many instances, their children had received appropriate services. These respondents recounted positive experiences with the system, including the view that the school provided useful information and assisted in transition from school to after-school programming. One mother noted that a teacher "with a human quality" was responsible for her child's progress, while another cited a good service coordinator who supported the mother during a difficult transition time.

Group 3, Andrea: La escuela ha sido una gran ayuda para nosotros porque de la parte donde venimos no habia escuela para él y él tenía muchas ganas y aquí he recibido mucha ayuda y parese que vamos bien hasta ahorita. (The school's been a great help to us because from where I am from there was no school to go to and he was quite motivated and I've received much help here and it looks like we're doing good for now.)

However, the pervasive sense of difficulties and negative treatment throughout the educational and services delivery systems was similar across participants. Although not all mothers provided critical examples of their own, no one ever rejected or challenged these interpretations when made by others.

Mothers' Suggestions for Improvement

A great deal can be learned about what is wrong with the current system from the parents' perspective by listening to what they have to say about making the system better. In terms of information transmission, pamphlets, handouts, and informational sheets were perceived as necessary, but also cold and impersonal mechanisms. Mothers, who often felt very isolated in the system, longed for contact with other mothers facing similar issues. They recommended acquiring information pertinent to their children's education, development, and training by talking to other parents and agreed that opportunities that promoted word of mouth and mutual helping would be most effective.

Group 2, Josefina: Estoy en días de decir, "Quién tiene hijos grandes como mi hijo para que me de una luz a ver como le hacen." (I've been meaning to ask for days, "Who has grown sons like my son who can give me the light to see how they do it.")

Mothers favored the idea of a parent group as a good way to exchange information about options and resources. In the eyes of the parents, the most attractive element of this model was its interpersonal dimension, in which information would be truly exchanged (two-way) mother-to-mother as part of an informal, friendly social interaction, rather than transmitted (one-way) expert-to-recipient. A group setting was also perceived as desirable because it put all participants on an equal footing (rather than expert and nonexpert) and acknowledged that all parents possessed some special understanding and insight into their children. After some prompting, mothers also acknowledged that written materials were sometimes problematic due to poor reading skills of the target audience. They suggested that informational audiotapes be supplied to parents. A third suggestion was that schools designate a special trouble-shooting individual to offer on-site help; this, too, reflected the need for personal, rather than purely factual, information provision.

Mothers felt that caseworkers and teachers needed more training about how to deal with children who have mental retardation. One mother thought it would be a good idea if part of their training consisted of actually living with a family of a child with developmental disabilities so that they could develop true understanding and empathy. Mothers expressed the conviction that training should not simply consist of additional knowledge about developmental disabilities but should also have "a human quality." They were also in favor of advocacy training to teach parents how to speak most effectively on their child's behalf.

Discussion and Conclusions

Regardless of whatever good intentions and efforts may exist among teachers and caseworkers of Latino young adults with developmental disabilities, results of this study suggest serious concerns held by mothers of these young adults regarding the educational and service systems. Above all, our research suggests a cultural "disconnect," at least for these mothers, which probably cannot be solved by simply providing informational pamphlets in Spanish, scheduling additional didactic presentations, or providing better referrals. Not only were these mothers disappointed with particular informational and system failures, but in their day-to-day interactions with Regional Center service coordinators and teachers, they operated within a context of mistrust toward and alienation from a system that they perceived did not care about their child.

In decades-old research cited earlier, researchers made similar observations and reached similar conclusions. The existence of these studies points to the intransigence of such cultural disconnects and provides indirect support for Kalyanpur and Harry's (1999) assertion that they are deeply embedded in all aspects of our professional values and behavior. For years, researchers and scholars have suggested ways that the educational and service systems could be made more compatible with and relevant to the expectations and needs of families from minority cultural backgrounds (Harry & Kalyanpur, 1994). It is disheartening that these recommendations continue to be mirrored in the statements of mothers in this study.

Further, it is important to recognize that the concrete nature of suggestions, such as expressing a personal interest in and developing personal knowledge of the child and family or recognizing and incorporating maternal ideas and insights about children, does not imply they can be satisfied by individual behavioral adjustments. Rather, we are dealing with philosophical views and attitudes strongly entrenched within the dominant culture that produced these educational and service systems. To build meaningful and successful relationships with parents from nondominant cultures will require more than cosmetic alterations in individual behavior, more than merely delivering services to them. Instead, what is necessary is a pervasive rethinking on all dimensions to achieve the "posture of reciprocity" advocated by Kalyanpur and Harry (1999, p. 498)

The theoretical model of parental participation in the special education/services systems is based on several assumptions that require careful reexamination. Three of the most important are the validity of professional authority, power, and expertise; the accuracy of the medical model for interpreting disability; and the legitimacy of advocacy as a mechanism to achieve rights (Skrtic, 1995). With regard to the first issue, if professionals retain control over decision-making and outcomes, then the parental role inescapably is restricted to one of acquiescence (Turnbull & Turnbull, 1997). If the setting, language, and rules of parental participation are determined primarily or exclusively by professionals, then it will always be the parents who must somehow learn to survive within formal educational and service systems (Harry, 1992a). In our study, this privileging of professional authority was reflected in parental concerns about inadequate or perfunctory communication from professionals, who appeared to be doing the least possible. Mothers had the sense that professionals just went through the motions because they, not the parents, retained the real ability to influence outcomes.

Further, positivist, objectivist assumptions about professionals' ability to correctly identify and implement universal truths regarding intervention with clients imply that certain kinds of knowledge are better than others and lead to attitudes that devalue or dismiss parental insights and observations (Kalyanpur, 1998). This phenomenon was reflected in our study through widespread perceptions that professionals consistently demeaned parents as ignorant and ill-informed. Yet our respondents clearly regarded themselves as possessing critical insights into and understanding of their children's needs that they wanted acknowledged and incorporated into educational and service plans.

In addition, the medicalization of disability may have indirectly influenced negative professional attitudes toward their clients themselves. The medical model is deficit-based and necessarily defines individuals with disability as lacking and inadequate (Bogdan & Knoll, 1995). Training in this model may produce attitudes of condescension and disapproving judgment toward individuals with disabilities, the kind of treatment that made mothers in this study report contempt and hostility toward their child. By contrast, our mothers, like many other parents, had the ability to see their child more holistically, simultaneously disabled and normal, with strengths as well as weaknesses.

Finally, the advocacy model of parental participation itself may be open to question on several grounds. First, following the above arguments, for this model to be effective, both parents and professionals must be acknowledged as having equal, although perhaps different, domains of expertise and power. This clearly was not the subjective experience of mothers in this study. Second, models based on confrontation and conflict may be unfamiliar and uncomfortable for individuals from other cultures. Like Latina mothers in previous studies (Harry, 1992b; Kalyanpur & Harry, 1999; Salend & Taylor, 1993; Zetlin, Padron, & Wilson, 1996), women participating in these focus groups did not enter the educational and service systems with the expectation or intention of confrontation and struggle nor did they seek these relationships. Rather, they hoped for warmth and caring and relationships infused with a personal interest in the well-being of their child. It was their negative experiences of indifference, poor communication, and contempt interacting with their belief in the primacy of the maternal–child relationship that transformed them into reluctant, but tenacious warriors. Like the mothers Harry (1998) interviewed, these women felt a powerful sense of protectiveness and commitment toward their child.

Interpretations of these data must be understood within the context and limitations of focus group methodology. First, and most important, is recognizing that focus group data cannot, and indeed should not, attempt to provide generalizable conclusions. Thus, we cannot claim that the interpretations arrived at in this study are pertinent to other Latina mothers of children with disabilities functioning in other environments and contexts. Related to this limitation of focus groups generally is a specific concern about the number of focus groups we were able to conduct. Although we are fairly confident in the theoretical saturation of our data, we would have preferred to have conducted one or two more groups. Difficulties in getting mothers to attend the focus groups made this impossible within our timeframe. Further, focus group data cannot account for how numerous sociocultural and historical factors may mediate interactions with and perceptions of the educational and delivery systems. Instead, these data must be understood as presenting the perspectives of the specific participants studied as a means of suggesting and illuminating important conceptual issues and perspectives.

Second, given the time and interaction constraints of a focus group, the attitudes expressed cannot necessarily represent the full range and complexity of participants' opinions (Carney et al., 1998). Research suggests that participants may generate responses favorable to the perceived viewpoint of the researchers, from a desire to promote a more positive encounter (Magaña, 1999). This phenomenon may have occurred in our focus groups, although examination of the question route (see Appendix A) makes clear that the emphasis of the researchers was weighted much more heavily toward transition than toward criticism of educational or service systems. In addition, as the section on collection procedures details, we took specific steps during the focus groups to avoid any drift toward group consensus based on perceived social desirability. Finally, although we attempted to recruit participants through the network of service agencies in California called Regional Centers, the majority of our mothers were recruited through an advocacy group that works in a complementary, though sometimes conflictual, capacity with the local Regional Center. This recruitment artifact might have meant that our mothers were more activist, more confrontational, and more vocal than Latina mothers generally. They may have been more knowledgeable and involved than is typical of their community. Nevertheless, it is possible to argue that the individuals who did participate were uniquely situated because of their leadership status and their ability to articulate insights and share perceptions that less involved and less aware mothers might not have been able to provide.

Perhaps the most intriguing question, reflecting an ongoing debate between incremental reformers and substantial reconceptualists (Andrews et al., 2000), is who, or what, should change in order to diminish the phenomenon of alienated advocacy identified in this study. Do Latina mothers need to become more socialized into the dominant American culture in order to develop an improved understanding of our educational and service systems? Or, on the other hand, do these systems need to make fundamental alterations in their methods of operation?

The first position assumes that the systems are fundamentally effective and successful and that the problem resides in the clientele whose cultural expectations and orientation "prevent" them from valuing the services provided. The second position implies that, seen through the eyes of individuals not immersed in the dominant cultural biases, the educational and service systems devised for children with developmental delays have some serious deficiencies. Of course, this question cannot be answered on the basis of this one exploratory study. Nevertheless, we believe that our findings provide a justification for additional and thoughtful investigation of this issue, with the goal of identifying appropriate adjustments in the educational and service systems not only for Latino children with developmental delay, but for children from all cultural backgrounds.

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Received 7/19/02, first decision 10/21/02, accepted 3/5/03.
Editor-in-charge: Steven J. Taylor

This manuscript was supported in part by National Institute of Child Health and Human Development Grant HD21324 awarded to Jan Blacher, principal investigator. We thank the mothers who contributed their time to this study and Fiesta Educativa for their role in recruiting participants.

Authors:
Johanna Shapiro, PhD (E-mail: jfshapir@uci.edu), Professor, Department of Family Medicine, and Director, Program in Medical Humanities & Arts, University of California Irvine, College of Medicine, 101 The City Dr., South, Rte 81, Bldg. 200, Ste 512, Orange, CA 92868-3298. **Lilia D. Monzó,** and **Robert Rueda, PhD,** Professor, University of Southern California Rossier School of Education, Division of Learning and Instruction, WPH 601, Los Angeles, CA 90089-0031. **Juan A. Gomez, BA,** Research Assistant and **Jan Blacher, PhD,** Professor, School of Education, University of California. Riverside, CA 92521.

Appendix A
Question Route: Transition to Adulthood

1. *Opening:* Please tell us your name, where you're from, and one thing you'd really like us to know about your son/daughter (alternative: the name of your son/daughter)?.
2. *Introduction:* What does the phrase "transition from being a school child to being a young adult" mean to you when you think of your son or daughter with mental retardation? *Follow-up:* What is your understanding of what is supposed to happen during this transition? *Follow-up:* How does that fit with what actually happened or is happening?
3. *Transition:* What do you know about your child's rights in terms of transition from school to other programs? *Follow-up:* What do you know about the laws regarding transition? *Follow-up:* What services do you think are provided as part of the transition process? *Follow-up:* What services do you think *should* be provided to help with this transition? *Follow-up:* How do you find out about such services? *Follow-up:* Does your child have a plan (IEP? other?) once he/she has finished school? What are its goals?
4. *Transition:* Think about when your other children, or nieces or nephews or the children of friends who do not have mental retardation, were leaving school and becoming young adults. What was that transition like for them? *Follow-up:* What typically happens to young adults during this time? *Follow-up:* What was that transition like for the family? *Follow-up:* How does this type of transition compare to the transition for your child with mental retardation?
5. *Transition:* Think about when you were younger. What was this transition like for you? *Follow-up:* Did you stay at home or did you leave at some point? *Follow-up:* When you did leave home, what was that like?
6. *Key:* All of your sons or daughters with mental retardation are now in the process of transitioning from being a school child to being a young adult. What is this transition like for them? *Follow-up:* Are they in or preparing to enter any kinds of special programs? If yes, what kinds of programs are they in? What has this transition (from school to program) been like? *Follow-up:* What is this transition like socially for this child (prompts: socializing, dating, living outside the home, working)? *Follow-up:* What does this transition feel like for you? *Follow-up:* How do you think your son/daughter with mental retardation feels about the transition?
7. *Key:* What are the most important aspects of this transition from school child to young adult for your son or daughter? *Follow-up:* What are the hardest parts? The best parts?
8. *Follow-up:* What are the most important aspects of the transition for you?

9. *Optional:* In what ways, if any, does discrimination toward your child because of his/her disability make this transition harder for them? For you?
10. *Key:* In what ways is your son or daughter's transition from school child to young adult important for your own well-being? For the well-being of your family? *Follow-up:* What kinds of things can go wrong in the transition that make things more difficult for you and your family? *Follow-up:* What needs to happen during the transition to reduce your stress and improve the well-being of your family?
11. *Key:* What would your life be like if your son or daughter with mental retardation were no longer living at home (note—this is a speculative question)? *Follow-up:* What would you look forward to? *Follow-up:* What might bother you?
12. *All things considered:* After participating in this discussion, what do you think is the most important aspect for your child of the transition from school child to young adult?