Stigma and Discrimination:

Perspectives From Mexican and Puerto Rican Mothers of Children With Special Needs

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The purpose of this study was to investigate the experiences of stigma-related discrimination in 50 Puerto Rican and Mexican single mothers of young children with disabilities. Mothers were interviewed on issues related to raising a child with disabilities. This was a preliminary exploration of the stories mothers told specifically related to discrimination. A qualitative analysis of the transcripts revealed clear evidence of discrimination as a result of culture, disability, and a combination of culture *and* disability. Professionals and strangers were responsible for the majority of the discrimination. Experiences were related to the higher number of interactions with service providers, lack of English language proficiency, being the solitary caregiver for their child with a disability, their status of "other," and the internalization of that status.

According to the latest report from the U.S. Census Bureau (2003), Latinos are the largest minority group in the country (see Note 1). They account for 13% of the population living in the continental United States. Latinos have higher unemployment rates, receive lower wages, and are more likely to live in poverty than non-Hispanic Whites (Therrien & Ramirez, 2001). The majority of the Hispanic population (35%) consists of youths under the age of 18 (Guzman, 2001). Latino children and youths experience poor outcomes in multiple areas, placing them at risk for poor cognitive and educational outcomes (Artiles, Rueda, Salazar, & Higareda, 2002; Fideler, Foster, & Schwartz, 2000; Frankenberg & Lee, 2002; Moore & Redd, 2002). They are more likely to live in poverty and face disproportionate health risk factors, including lack of access to care and higher rates of asthma and diabetes, and are at high risk for behavioral and developmental disorders resulting in early placement in special education (Flores et al., 2002; Moore & Redd; Therrien & Ramirez). Furthermore, several studies report that discrimination is a factor for a majority of Latinos, resulting in significant negative impact on their success in both school and the workplace (Brodie, Steffenson, Valdez, Levin, & Suro, 2002; Villarruel et al., 2002).

The increased risk of developmental and behavioral disorders results in early and possibly frequent interactions with a variety of service providers in both early intervention and pre-K–12 settings. These interactions may be difficult for parents from different cultural and linguistic backgrounds who are unfamiliar with the special education system. Prevailing views by professionals of culturally and linguistically diverse groups of parents as in need of "fixing" indicate a continuing lack of cultural awareness that may result in stigmatization and subsequent discrimination (Correa, 1992; Ferguson, 2002; Harry, 1992, 1997; Kalyanpur, 1998; Kalyanpur, Harry, & Skrtic, 2000; Kalyanpur & Rao, 1991; Thorp, 1997; Villenas, 2001). Perceptions of discrimination and bias play a role in parent involvement and advocacy, both of which are necessary in the special education system. For Latinos, lack of English language proficiency may further impede their ability to engage fully in the education of their child and may hinder receipt of available services for their child.

For single mothers of color, the situation becomes even more complex. Their solitary status as primary caregiver places these mothers in a position of increased interactions with service providers and the special education system. Single mothers, especially single mothers of color, are often negatively stereotyped, further increasing the possibility of stigmatization and higher levels of discrimination (Dowd, 1997; Gottlieb, 1997; Polakow, 1993; Sloan, Jason, & Addlesperger, 1996).

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There is scant research specific to the Hispanic population that looks at multiple stigmatizing factors that may result in increased levels of discrimination. Furthermore, little is known about the interaction of culture and disability on stigma and discrimination among Latinos. This article describes reported experiences of stigma-related discrimination by single Mexican and Puerto Rican mothers of a young child with a disability and their responses to those experiences.

Stigma

Goffman (1963) defined stigma as a discrediting attribute assigned by society to those who differ in some manner from society's expectations, customs, and mores. It results from a social categorization process that allows for the quick identification of those who are similar and those who are different and can therefore be considered as "others." It is not simply the act of categorization that results in stigmatization of certain groups, but, rather, the coupling of negative value judgments with particular characteristics that results in an adverse reaction to difference (Goffman; Susman, 1994). The adverse reaction takes the form of discrimination, or beliefs, attitudes, and actions directed at individuals due to "phenotypic characteristics or ethnic group affiliation" that result in disparate life chances or unequal outcomes (U.S. Department of Health and Human Services, 2001). Disability and ethnicity are two such characteristics used to categorize individuals into stigmatized groups. There are multiple other stigmatizing characteristics, including female gender and single motherhood.

Link and Phelan (2001a, 2001b) developed a conceptual framework for stigma that addresses the social element inherent in the stigmatization process. Their framework is based on interrelated components that look beyond the individual, and it addresses the role of power in discrimination. Within their framework, stigma is conceptualized as a five-stage process: (a) Differences are identified and labeled; (b) differences are linked to negative stereotypes; (c) stereotyping allows for categorization and placement of stigmatized individuals into distinct groups, separate from the dominant culture; (d) separation allows for loss of status and discrimination; and (e) a power differential exists between the labeler and the labeled, making discrimination possible.

Link and Phelan (2001a, 2001b) identified three sources of discrimination: (a) direct or overt, (b) structural or systemic, and (c) social–psychological processes operating through the stigmatized individual. The final source, social–psychological processes, describes socialization of stereotypical perceptions and the internalization of such perceptions resulting in behaviors that may lead to self-perpetuating discrimination. With this source of discrimination, individuals who believe that they will be discriminated against may respond by withdrawing and avoiding social contact, thereby negatively affecting their support network and increasing their levels of stress.

Fear of stigmatization and subsequent discrimination may influence how individuals interact with others. Concealment of the condition, advocacy, and withdrawal have been identified as possible responses to real or perceived stigmatization and discrimination (Green, 2001, 2002; Link, Cullen, Struening, Shrout, & Dohrenwend, 1989). Green (2001, 2002) described how the way in which the effect of individual responses to stigmatization and discrimination is important. Her study found that mothers of children with disabilities who feared discrimination were less likely or willing to interact with others. Their children were also less likely to interact with peers. This response has implications for both the mother and the child, possibly limiting opportunities and life chances.

Study Purpose

Disability, ethnicity, female gender, and single motherhood can be considered stigmatizing characteristics that may result in discrimination. The special education system can also be stigmatizing and discriminating. Being a single Latina and having a child with a disability are compounding factors that may have cumulative effects. Currently, little is known about the interactions among these four characteristics. The purpose of this study was to describe, through qualitative methods, the basis of reported experiences of discrimination by Mexican and Puerto Rican single mothers of a child with a disability and to examine how these mothers responded to their experiences.

Method

Participants

This study utilized existing data from the Latino Family Study Project conducted by the University of North Carolina, Chapel Hill, and the University of Florida (Bailey, Skinner, Rodriguez, Gut, & Correa, 1999). The purpose of the project was to describe and explain associations between child and family characteristics, beliefs about disability, perceived family needs, and use of professional service (Bailey et al., 1999; Bailey, Skinner, Rodriguez, Gut, & Correa, 1999; Skinner, Bailey, Correa, & Rodriguez, 1999). It employed a mixed method design involving in-depth interviews conducted at two points in time.

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The participants in the original study consisted of 250 Mexican or Puerto Rican parents of a child with a disability who were receiving special education services through Part C (early intervention) or Part B (ages 3–5 years) of the Individuals with Disabilities Education Act (IDEA). Participants were recruited through phone contacts of personnel from various agencies and through information packets distributed to school districts, early intervention programs, religious institutions, and private organizations. Upon receipt of verbal consent to contact, the researchers or an identified contact person from the referring agency met with the family to verify eligibility, obtain informed consent, and schedule the interview. Of the 250 participants, 200 were married and 50 were single mothers.

This article focuses on the 50 single mothers (25 Mexican and 25 Puerto Rican) from the original study who participated in the initial round of data collection. Demographic information for the single mothers is displayed by country of origin in Table 1. Both groups were similar in socioeconomic status, mean age for mother and child, child's behavior rating, and years in the United States. Statistically significant differences were found in location of residence, type of community they lived in, and education level. The majority of the Mexican mothers resided in Arizona (84%), whereas all of the Puerto Rican mothers resided in Florida. A higher percentage of the Puerto Rican mothers lived in suburban or urban areas compared to the Mexican mothers (91.7% vs. 76.0%, respectively). Mexican mothers reported lower levels of education. A larger percentage of Mexican mothers (46%) reported finding speaking English to be extremely easy, compared to the Puerto Rican mothers (20%). The majority of the interviews were conducted in either Spanish (Mexican mothers 56%, Puerto Rican mothers 72%) or Spanglish, which is Spanish characterized by numerous borrowings from English (Mexican mothers 36%, Puerto Rican mothers 16%).

Measures

The interview protocol was 16 pages long and consisted of 160 questions, both open-ended and embedded Likert-style survey questions. The protocol addressed five domains: the child, initial identification/perception of cause, help-seeking behaviors, family life, and ideas and concepts of childrearing. Interviews were conducted in Spanish, English, or a combination of both based on the parent's preference and were scheduled to accommodate the parents. Transcripts were translated into English and then reviewed by the interviewer for accuracy.

TABLE 1. Family and Child Variables of Single Mothers by Country of Origin

Variable	Mexican	Puerto Rican	Total
Family on public assistance (%)	94	88	91
State of residence (%)			
Florida	16.0**	100.0**	58.0
Arizona	84.0**	0.0**	42.0
Metro status (%)			
Rural & small town	24.0**	8.3**	16.3
Suburban & urban	76.0**	91.7**	83.7
Socioeconomic status			
Hollingshead score & (*SD*)	17.2 (8.3)	20.9 (11.6)	19.1 (10.0)
Highest education level completed	10.0 (3.8)*	12.0 (2.8)*	11.0 (3.3)
Mother/age in years & (*SD*)	27.7 (9.3)	27.3 (6.8)	27.5 (8.1)
Child/age in years & (*SD*)	2.8 (1.6)	3.1 (1.3)	3.0 (1.5)
Child gender (% female)	44.4	29.2	36.7
Vineland Adaptive Behavior Scales			
Total score mother's report & (*SD*)	63.5 (17.6)	61.3 (13.7)	62.4 (15.7)
Language proficiency (self-report) (%)			
None–some difficulty	54.0	80.0	67.0
Extremely easy	46.0	20.0	33.0

Note. $N = 50$. *Vineland Adaptive Behavior Scales* (Sparrow, Balla, & Cicchetti, 1985).
*$p < .05$. **$p < .01$.

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Procedure

Two researchers, one of whom participated in the original study, conducted this study. The researcher unfamiliar with the original study read 10 randomly selected transcripts to determine if any theme emerged beyond the specific information sought by the original protocol (Strauss & Corbin, 1998). A portion of the protocol dealt specifically with social acceptance and perceptions of discrimination (see Table 2), but the holistic analysis of the transcripts revealed that discrimination was a very real part of these women's lives and substantial enough to warrant further analysis. From these findings, the following two research questions were posed:

1. What are the reported experiences of perceived discrimination among Latina single mothers of young children with disabilities?
2. How do Latina single mothers of young children with disabilities respond to experiences of perceived discrimination?

Analysis

Twenty transcripts (10 per ethnic group) were randomly selected and independently analyzed and coded by both researchers. Analysis utilized grounded theory methodology (Strauss & Corbin, 1998), and entailed multiple iterations of the data (see Table 3). Researchers conducted an initial reading to become familiar with and gain a sense of the mothers' responses, as well as to begin to identify possible themes. Preliminary findings were discussed. Both researchers conducted a second reading and identified specific quotations or sections of the transcripts that indicated experiences of discrimination and contained sufficient context to allow for interpretation. Experiences of discrimination were defined as any exchange indicating disparate treatment that could or did affect life chances. Each quotation was coded based on the source of the discrimination, the recipient of the discrimination, the basis of the discrimination, where the experience occurred, and how the recipient responded to the discrimination. These data were then compared to ensure trustworthiness of the data. Discrepancies were discussed and consensus reached.

All of the transcripts were then analyzed and coded in this manner by one of the researchers. The 50 transcripts totaled 1,239 pages, from which 135 pages of quotations emerged. Upon completion of the analysis, 20% of the transcripts were again randomly selected and analyzed by the second researcher to ensure reliability. Most quotations provided information describing the perceived discrimination, including who was responsible for delivering the discrimination, the person to whom the discrimination was directed, the context of the discrimination, the basis of the discrimination, the type of discrimination, and the response. Therefore, codes were sorted according to each of those categories. Any instance of perceived discrimination was coded as such and no attempt was made to determine a threshold level indicating at what point an instance of discrimination would be determined as significant enough to warrant coding.

Researcher Identities

One of the critiques of studies on stigma is that those who study it rarely belong to the stigmatized group (Kleinman et al., 1995; Link & Phelan, 2001b). Both researchers for this article are Latinas and both have experience as teachers in special education. One of the researchers is also a mother, although not of a child with a disability. Such multiple identities are part of every researcher and play a role as he or she goes about the task of analyzing and interpreting data (Harry, 1996). Minimal participation in the data collection process (conducting one interview and assisting in two others) in the original project by one of the authors would indicate that her identity as a Latina with experience in special

TABLE 2. Social Acceptance and Discrimination Questions

Number	Protocol question
127	If you spoke perfect English and didn't tell anyone that you are of Latino background, do you think that people would accept you as they would any other American?
128	Why do you think you would definitely not be accepted like any other American? And your children when they become adults?
129	Have you felt discrimination for being [ethnicity]?
130	For having been born in [country of origin]?
131	Why do you think that you have been discriminated against?

Note. Questions 127, 129, and 130 have Likert-scale responses. Question 128 is skipped if the response to 127 indicates full acceptance. Question 131 is skipped if the response to 130 indicates no experiences of discrimination.

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education did not influence maternal responses. However, membership in these groups could have affected analytic interpretations. Both researchers were cognizant of their individual identities and thus engaged in self-reflection and discussion to ensure that interpretations were, to the extent possible, accurate portrayals of the women's lived experiences.

Results

Research Question 1

What are the reported experiences of perceived discrimination among Latina single mothers of young children with disabilities? Experiences of perceived discrimination revolved around three themes: culture, disability, and a combination of culture and disability. These experiences involved all three sources identified by Link and Phelan (2001a, 2001b): direct discrimination, structural discrimination, and social–psychological processes within the individual. Although many of the mothers discussed a lack of support due to their status as a single mother and the fact that their families were still in either Mexico or Puerto Rico, there were no instances that clearly revealed discrimination resulting from their status as a single mother. All but three of the Mexican mothers and two of the Puerto Rican mothers reported some experience of discrimination.

Discrimination Based on Culture

Culture is used here as an umbrella term encompassing ethnicity, language, customs, and appearance. Discrimination based specifically on culture usually took place in the context of society at large. It often involved strangers and was evident in a variety of locations, including place of employment, department stores, restaurants, and libraries. Many mothers recounted experiences of direct discrimination related to specific incidents that were hurtful, disrespectful, and demeaning. One mother spoke of being called a *wetback* at her place of employment. At a local fast-food restaurant, one mother was told, "If you don't bring your interpreter, we are not going to help you." Another mother described how a store employee told her that "customers were complaining because there are more and more Latinos. [Customers] don't like it when [employees] speak Spanish."

The mothers described similar situations about their attempts to obtain social services. Maria described one such encounter with a social services employee (see Note 2).

> That day, I went in order to pick up my food stamps. I had always used the same card in order to pick them up, but this day a different lady was there. When she checked the card, she told me something—I could not understand her very well—so I told her that I did not speak English that well. She just grabbed the card and threw it at me [*me la zumbó*]. And she did not explain anything to me.

Elena shares this experience at her place of employment, which has implications for life chances and financial status:

> There are some customers which come up to me and say they don't want any Puerto Rican to clean their car. They look for an American boy to help them.

Discrimination in the form of social–psychological processes was evident in the stories several of the moth-

TABLE 3. Iterative Process

Level	Purpose	Process
First iteration	Sample analysis	• 10 transcripts randomly selected and read for emerging themes beyond scope of original study
Second iteration	Initial content analysis	• 20% of transcripts randomly selected and independently analyzed for themes • Results compared and discussed
Third iteration	Descriptive coding	• Quotations from sample transcripts identified and independently coded • Results compared and discussed
Fourth iteration	Content analysis	• Coding of all transcripts by one researcher
Fifth iteration	Reliability	• 20% of the interviews (10 from each group) randomly selected and coded by second researcher • Results compared and discussed
Sixth iteration	Categorization	• Codes are sorted into categories

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ers told of being part of the "other," with no specific incident or person in mind. They referred to the discrimination in terms of "them." Some seemed puzzled, unable to explain exactly why people treated them with disrespect:

> They treat you weird, they look at you long, and you know.
>
> Maybe because of my way of dressing. I don't know. Maybe it is because of customs.
>
> Just the way people look at you when you are in certain areas of town.
>
> I like to chat with different people, and I've noticed that they cut their conversations with me and they don't want to continue to talk to me. I think that's strange.

Some felt there was an automatic assumption regarding language proficiency based simply on appearance. Although most of the mothers did not speak English, a few did. One mother describes being at a library and having two women standing next to her begin talking in English about her hair:

> I don't know how she can stand that hair in this heat. . . . I turned around and told her, I feel perfectly fine with my hair this way. . . . She thought I wasn't going to understand her.

Structural discrimination, which has implications for life chances, was apparent in the story Isabel told of being overlooked for a raise:

> The girl I work with, she's White. Some people would rather speak to her than come to me and I'm nice to everybody. She got a raise and I had been there longer. When I asked the owners, who are White, about [why I didn't get a raise], they said they didn't think about it.

Doris describes the following exchange demonstrating disparate treatment at a doctor's office:

> I arrived 15 minutes late. And another one, who was from here (American), arrived 30 minutes after the appointment. Well, she got in and I did not. And the receptionist was even yelling at me: "For the next one, come earlier. Take the bus." I don't know the bus route; I have to ask for a ride. She replied, "Learn."

Many mothers felt they would not be accepted, even if they spoke perfect English, because of their appearance. Consistently, they brought up their features and skin color as indicators of their ethnicity that would immediately single them out and result in differential treatment.

One mother said, "They will always know that I am Latina, even if you take away my accent. It's a *mancha del platano*." The literal translation of *mancha del platano* is a stain on a plantain. In Puerto Rico it is a saying that refers to how your hands stain from peeling and cooking so many plantains. What she means here is that she cannot hide her ethnicity; it is always evident, there for all to see and react to. Differences in treatment based on skin color were exemplified by one mother's comment that "when one is a little dark, they treat you like garbage."

Instances of perceived discrimination related to culture were attributed to ethnicity, language, customs, and/or appearance, with language and appearance accounting for a larger portion of these experiences. Discrimination was direct, structural, and/or a result of social–psychological processes within the individual. Experiences took place in public settings, including service agencies, and had implications for life chances.

Discrimination Based on Disability

As with discrimination based on culture, discrimination based on disability was apparent in interactions with various individuals and entities. Strangers and professionals were accountable for the majority of the interactions, followed by people within the family, specifically the father. Discrimination as a result of disability also took on various forms.

Similar to discrimination resulting from culture, a majority of the discrimination from people in society was direct in nature. One mother described an exchange between herself and a stranger as they were waiting for a city bus. "I had my son; some lady asked me why was he so little. I said, 'Well, he was premature.' 'Sure,' she said, 'You were probably doing drugs.' " Discrimination related to social–psychological processes was also evident within this theme. Although the primary recipient of discrimination related to disability would be considered the child, the mothers, by virtue of their adult status, recognized and responded to the discrimination. Elena demonstrates this reaction and response in the following comment:

> There are times in which people look at me like "What is this? You don't know how to control your boy?" Well, I cannot put a sign on him saying "insane" or a poster saying this child is autistic. . . . He doesn't need to know that he has a label.

Most mothers felt uncomfortable and unsure how to respond to questions about what was "wrong" with

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their child. One mother did not want to say her child was blind because others "would pity him." Faced with inquiring adults, the mothers also had to deal with the reactions from other children. One mother told a story about going to enroll her child with hydrocephaly in school and being surrounded by children who began shouting, "Here comes the monster; look at how big her head is." She went on to explain that although she cried, the greater emotion was anger at her impotence in not being able to say anything to them. Even so, there were minimal experiences related to discrimination by other children. This may be a result of the isolated status of the child with the disability; most mothers explained that they did not allow their child to interact a great deal with other children.

Many mothers spoke of experiencing frustration and disappointment upon learning the initial diagnosis of their child. Their frustration continued as they attempted to obtain services for their child. They were left feeling that no one really listened to them and that many professionals simply placated them. Most of the mothers told of minimal expectations in the prognosis of their child. One was told, "Don't get your hopes up; he's not going to live." Consistently, the messages they received dealt with the child's inabilities: " 'He can't do this; he won't be able to do that.' They treat you like your child is useless."

Prior to formal diagnosis, many of the mothers reported being instinctively aware that their child was in need of services. Professionals occasionally dismissed the mothers' concerns as overreactions or needless worrying. One mother was told to "take two Tylenol and relax" when attempting to explain her concerns about her child. Another mother of a child with autism described this interaction with her pediatrician:

> I asked the doctor to examine her. I told him that she had something. I explained what she did and her behavior. "The girl is fine; she doesn't have anything," he said. I told him that she had something because she didn't talk. [The doctor said,] "She doesn't want to talk to me because I'm a stranger. . . ." "I live with her every day. I know that she's got something," I said. "No, she's normal," he said. "I have a four-year-old and she's like that sometimes."

Discrimination Based on Disability: Fathers' Responses

Although occasionally mothers spoke of family members who became distant or were fearful of caring for the child, the majority of instances of discrimination based on disability by people within the family were by the father. In these situations, the end result was rejection of the child by the father and separation or divorce from the mother. Discrimination by the father is closely mirrored in Link and Phelan's (2001a, 2001b) conceptual framework. The child was labeled as different by virtue of his or her disability. There was an adverse reaction to the disability as a result of associated negative stereotypes. The ultimate result was a rejection of the child, which also had social and financial repercussion for the mother, as indicated by several respondents:

> Her father completely refused to acknowledge her.
>
> After he found out what was wrong, he backed off.
>
> He just couldn't handle it.
>
> He didn't accept that his child could have that impediment, and that's the reason he left. . . . He couldn't stand it.

In most instances, it was the father's decision to leave the family. Occasionally, the mother would make the decision to leave or have the father leave. The mothers had assumed full responsibility for taking care of their child and had little patience for a father who was not equally committed. Faced with such a decision, one mother stated, "I had to choose between a child with problems and a man acting like a child. I dedicated my life to my child.... 'You can go ahead without me.' " Another told her husband, "This is my child, and he needs me more than you need me."

Courtesy stigma, or stigmatization by virtue of close association to a stigmatized individual, was apparent in discrimination based on disability. In this category, instances of discrimination were directed specifically at the child, but because of the mother's role as the caregiver and the young age of the child, the mother experienced the discrimination more so than the child. Again, instances of discrimination were direct, structural, and/or a result of social–psychological processes within the individual. Experiences took place in public, at the offices of service providers, and at home. Many mothers indicated that the fathers were unable to cope with the disability of the child. Their status as a single mother was often a direct result of the father's response to the child's disability.

Discrimination Based on Both Culture and Disability

Perceived discrimination resulting from the interaction of culture and disability most often took place in the context of obtaining services. Not surprisingly, the language barrier was the main factor as mothers attempted

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to maneuver the social service system. They reported receiving most, if not all, of the information pertaining to their child in English. One mother noted that even the evaluations were in English. As one of the few mothers who spoke both languages, her concern was for "those that didn't." One mother said all of the papers she received were "all in English . . . I don't know; I don't sign them." Another spoke of trying to call somewhere to get services, but there was no one available who spoke Spanish: "I felt terrible . . . call a nurse but how was I to speak to her?" One mother described how during an appointment "the nutritionist tore up my papers and told me to get out. . . . 'When you learn to speak English, come back.'"

Again, discrimination experienced as a result of both culture and disability was direct, structural, and/or a result of social–psychological processes within the individual. The majority of the instances in this category occurred during interactions with professionals and service providers. The mothers' role as the primary caregiver of the child, the need for medical and support services, and, for many, the lack of a local informal support network all play a role in the cumulative effects of discrimination in this category.

Summary

The experiences of perceived discrimination among Latina single mothers of young children with disabilities were a result of culture, disability, and the interaction of culture and disability. Discrimination related to culture centered on issues of language and/or appearance, involved society at large, and had clear implications for life chances. Discrimination related to disability was directed at the child but experienced by the mother as a result of her caregiver role. Discrimination related to both culture and disability was most apparent with service providers and had clear implications for help-seeking behavior. Discrimination was direct, structural, and/or a result of social–psychological processes within the individual.

Research Question 2

How do Latina single mothers of young children with disabilities respond to experiences of perceived discrimination? Responses were not clearly evident in each instance of perceived discrimination. Coded responses were categorized as either deliberative or assertive. For the purposes of this study, a deliberative response was one that was nonconfrontational. Deliberative responses may seem passive, giving the impression of a level of acceptance. It is our view that there is not sufficient information to identify these responses as passive, because it is quite possible that the passive response was the mothers' survival mechanism or their means of maneuvering through an unfamiliar system. For this reason, we have chosen to use the word *deliberative,* rather than *passive.*

Deliberative responses included instances in which the mothers described feeling embarrassed, being fearful of losing services, or simply feeling hurt. "It makes me feel bad, but I try not to show it."

Sometimes, lack of language proficiency affected the women's ability to respond to situations in a more assertive manner. Juanita's response illustrates this in the following remarks:

> Because if I knew how to respond when they come out with their crude remarks—because I don't understand you, or I don't know what you're saying to me. If I knew how to answer them, I think they would help me. Because if I knew how to speak English like I know how to speak Spanish, I'm sure they would have paid attention to me.

Some of the mothers spoke of being more comfortable in segregated or solitary settings, where they or their child were less likely to face discrimination. When asked who her neighbors were, one Mexican mother responded, "Mexicans. All. This is fine. Less trouble." Another explained that she had not gone to a meeting for parents with children with a disability "because all the cases are Americans, the majority. And to avoid the way that they speak to me, it's better that I stay in my house."

Many preferred to avoid social situations due to the reactions they received from strangers and friends alike. Margarita's comments relating to people within her community were similar to other mothers':

> I go out less. . . . I try to bother the others as little as possible. They make faces . . . because they don't understand about a disabled child. They get upset and they think he must be dumb, or he must be stupid, and I try to avoid this. He doesn't need anyone else but us.

Assertive responses were more often directed at a professional when the mothers were in need of a diagnosis or of services for their child. One mother explained how she caused a "commotion" when she was unable to enroll her child in an early childhood program and the school finally admitted the child. Another mother said, "They call me 'annoying.'" When faced with the possibility of her son having to change schools as a result of an evaluation with which the mother did not agree, the mother emphatically said, "I am going over her head if they do that."

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Summary

Results reveal that the single mothers in this study had multiple experiences of discrimination. Experiences were related to the higher number of interactions with service providers, the lack of English language proficiency, being the primary caregiver for their child with a disability, and their status of "other" and the internalization of that status. This study can be construed as a preliminary exploration of experiences of discrimination of Latinas demonstrating the need for future research in this area.

Discussion

Data analysis suggests that discrimination is complex and multifaceted. The reported experiences of discrimination were based on culture, disability, and/or a combination of culture and disability. There was not sufficient information to ascertain the role of single-mother status on discrimination, because there were no experiences that could be specifically attributed to being a single mother. It is important to note that a majority of the mothers received public assistance, increasing their interactions with service providers. Some of the reported experiences of discrimination by service providers as a result of culture may have been directly related, ipso facto, to interactions with public assistance providers. In other words, if these mothers were not on public assistance, some of those interactions would not have occurred.

Professionals and strangers were responsible for the majority of the discrimination experienced by these mothers. Discrimination was directed at the mother as well as the child, although it can be said that mothers bore the brunt of all instances of discrimination by virtue of their role as guardian and protector of their child. Fathers were also responsible for discrimination directed at the child with the disability, although to a lesser degree. Rejection of the child by the father may have resulted in economic hardship for the mother, making it necessary to receive public assistance and thus increasing her interactions with service providers.

A majority of the mothers experienced some form of discrimination that they attributed to their ethnicity. Although lack of English proficiency was seen as a factor in discrimination, the fact that the mothers looked different from the majority culture seemed to play a more important role in their perception of others' reactions to them. The color of their skin was repeatedly cited as a major factor in being viewed as different and unable to fit in. Their customs were also cited as factors in discrimination. Oftentimes, strangers and professionals used these differences as justification to refuse services ranging from being served at a fast-food restaurant to enrollment in an early childhood program. This would indicate that English-language proficiency would not be sufficient in reducing discrimination and ensuring equitable treatment. It may be that physical characteristics and skin color play a larger role in discrimination than language alone. This begs the question: If families interviewed in this study spoke English, would they continue to experience this level of discrimination?

Responses to the discrimination were varied and replicated those identified in previous studies (Green, 2001, 2002; Link et al., 1989). Concealment was evident only in regard to the child's disability, because the majority of the mothers felt that their ethnicity could not be concealed, because of either their appearance or their lack of English-language proficiency. This lack of English- language proficiency also made it difficult to assume an advocate role.

Socialization as a stigmatized group resulted in some mothers purposely avoiding social interactions, preferring to remain either alone or with others from their own cultural group. Therefore, it is possible that a lack, or limited number, of reported experiences with discrimination by mothers who were isolated was a result of minimal interactions with members of the dominant culture. If these mothers were in more heterogeneous settings, would the level of discrimination increase?

Even if the mothers were not physically isolated, their lack of proficiency in English resulted in verbal isolation, and many expressed dismay that none of the documents they received were in Spanish. One mother specifically stated that she did not sign anything sent home by the school for that reason. Although her reaction is understandable, it may convey to the school that she is not interested in her child's education, thus furthering a deficit view of culturally and linguistically diverse families.

Researchers attempted to categorize responses as either assertive or passive. This was difficult to do because some passive responses may have been deliberative in nature. It may be that mothers believed that assuming a passive stance would help ensure receipt of services. Yet, a passive response may be misconstrued as a sign of compliance or indifference. As such, the rationale for their responses may be as important as, or more important than, the actual response. How do preconceived values and beliefs, by both the mothers and those they interact with, affect communication patterns and responses? Also, how do those responses support or negate stereotypical views of both culturally and linguistically diverse individuals and service providers?

Professional dominance (Freidson, 1970; in Seligman & Darling, 1997) was evident as mothers, instinctively aware that their child had special needs, attempted to obtain a diagnosis. Mothers recounted numerous in-

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stances in which the level of expectations differed significantly between the mother and the professional. Their attempts to prove that their children could do more than expected were often met with doubting looks by the service providers. These reduced expectations on the part of professionals could be considered discriminatory because they may limit child outcomes. Determining the appropriate level of expectations is a difficult task that must balance reality with hope. Experiences of discrimination when seeking services may result in avoidance of or delay in seeking services. Is it possible that undesirable conditions in the intervention setting make seeking help far less desirable than it would otherwise be? Does it keep mothers from seeking services elsewhere?

Country of origin did not seem to be a variable that differentiated the level or type of discrimination experienced. Even though these women appeared to be experiencing discrimination at similar levels, examination of a larger sample might have revealed differences based on country of origin. Moreover, a more heterogeneous group of single Latina mothers might have demonstrated a greater range of stigmatization and discrimination. Future work examining level and/or form of discrimination reported by single mothers versus married mothers may provide valuable information on specific supports needed based on marital status.

The interview protocol contained a variety of open-ended questions and two survey questions related to acceptance and discrimination. In several instances, responses to these two forced-choice questions were negative, indicating that they had not experienced discrimination. This was inconsistent with the information obtained through the open-ended questions, a finding demonstrating the need for qualitative methods when researching discrimination.

Limitations

This study did not seek to make generalizations. Rather, it was meant to provide a window into the experiences of a small group of single Latino mothers with a child with a disability. The study has several limitations. The sample size is small and is drawn from two states with large Mexican or Puerto Rican populations. The study only looks at two Hispanic groups. It is possible that results may vary in states with smaller Hispanic populations and may vary based on country of origin and immigration status.

The fact that this was a secondary analysis meant there was no opportunity to probe or seek clarification of responses. There was no opportunity to conduct member checks on the findings. As a result, interpretations of the reported experiences are based on the researchers' perspectives. Furthermore, although the interviewer had an opportunity to review and correct the translated transcripts, it is possible that some subtle aspects of stigma and discrimination may have been lost in the translation.

Conclusions

As noted, all of the children with disabilities were below 6 years of age, with the average age being 3. A majority of the children was currently being served in pre-K settings. Mothers had developed specific behaviors in response to their relationships with service providers and the majority culture—behaviors that will play a role in the relationships that develop once their child enters school and the shift in focus is made from the family to the child. Of concern are the possible implications with regard to placement as these children progress through the educational system. This is a critical issue. The mothers in this project were involved with the special education system at a very early stage of their child's life. Early experiences, either positive or negative, set a precedent for expectations of future interactions. If these experiences are fraught with bias and discrimination, it is likely that mothers may become defensive, distrusting, and suspicious of future interactions with professionals. It is possible that they may become overwhelmed and withdraw, believing that they are unable to help their child, given the bureaucracy and barriers inherent in the system.

The preliminary findings of this study lend support to the necessity for developing a research agenda to better understand the impact of culture, social issues, stigma, and discrimination for the purpose of establishing that they exist and acknowledging the need for action. Researchers must move beyond identifying barriers such as lack of English-language proficiency and begin to study the complexities and multiple faces of discrimination experienced by Latinos. Understanding the complexity of discrimination requires moving past the assumption that these families will experience discrimination simply as a result of their ethnicity. Multiple stigmatizing conditions increase the likelihood of experiencing discrimination. Thus, it is necessary to examine the *interaction* of ethnicity and disability as stigmatizing conditions, considering that experiences with frontline service providers due to the disability may shape future attitudes and biases as families begin their journey within the special education system.

As Latinos interact with the macroculture of the United States, the issue of power and the role it plays in stigmatization, discrimination, and disparate life chances must be examined. It is imperative that we identify how to best give culturally and linguistically diverse families the "cultural capital" to understand the system so that they may advocate for the betterment of themselves and their children. ◆

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NOTES

1. The terms *Latino,* or *Latina,* and *Hispanic* are used interchangeably in this article, although *Latino/a* is used predominantly throughout.
2. Pseudonyms have been used throughout.

REFERENCES

Artiles, A. J., Rueda, R., Salazar, J. J., & Higareda, I. (2002). English-language learner representation in special education in California urban school districts. In D. J. Losen & G. Orfield (Eds.), *Racial inequity in special education* (pp. 117–136).

Bailey, D., Skinner, D., Rodriguez, P., Gut, D., & Correa, V. (1999). Awareness, use, and satisfaction with services for Latino parents of young children with disabilities. *Exceptional Children, 65,* 367–381.

Bailey, D. B., Skinner, D., Correa, V., Arcia, E., Reyes-Blanes, M. E., Rodriguez, P., Vásquez-Montilla, E., & Skinner M. (1999). Needs and supports reported by Latino families of young children with developmental disabilities. *American Journal on Mental Retardation, 104*(5), 437–451.

Brodie, M., Steffenson, A., Valdez, J., Levin, R., & Suro, R. (2002). *2002 National survey of Latinos* (No. 3300): Washington, DC: Kaiser Family Foundations and Pew Hispanic Center.

Correa, V. (1992). Cultural accessibility of services for culturally diverse clients with disabilities and their families. *Rural Special Education Quarterly, 11,* 6–12.

Dowd, N. E. (1997). *In defense of single-parent families*. New York: New York University Press.

Ferguson, P. M. (2002). A place in the family: An historical interpretation of research on parental reactions to having a child with a disability. *The Journal of Special Education, 36,* 124–130.

Fideler, E. F., Foster, E. D., & Schwartz, S. (2000). *The urban teacher challenge: Teacher demand and supply in the great city schools*. Retrieved October 15, 2002, from http://www.cgcs.org

Flores, G., Fuentes-Afflick, E., Barbor, O., Carter-Pokras, O., Claudio, L., Lara, M., et al. (2002). The health of Latino children: Urgent priorities, unanswered questions, and a research agenda. *Journal of the American Medical Association, 288,* 82–90.

Frankenberg, E., & Lee, C. (2002). *Race in American public schools: Rapidly resegregating school districts*. Retrieved November 10, 2002, from http://www.law.harvard.edu/civilrights

Freidson, E. (1970). *Professional dominance*. Chicago: Aldine.

Gottlieb, A. S. (1997). Single mothers of children with developmental disabilities: The impact of multiple roles. *Family Relations, 46,* 5–12.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity.* New York: Simon & Schuster.

Green, S. E. (2001). 'Oh, those therapists will become your best friends': Maternal satisfaction with clinics providing physical, occupational and speech therapy services to children with disabilities. *Sociology of Health & Illness, 23,* 798–828.

Green, S. E. (2002). "What do you mean 'what's wrong with her?' ": Stigma and the lives of families of children with disabilities. *Social Science & Medicine (1967), 57,* 1351–1374.

Guzman, B. (2001). *The Hispanic population* (No. C2/KBR/01-3). Washington, DC: U.S. Census Bureau.

Harry, B. (1992). An ethnographic study of cross-cultural communicating with Puerto Rican-American families in the special education system. *American Educational Research Journal, 29,* 471–494.

Harry, B. (1996). These families, those families: The impact of researcher identities on the research act. *Exceptional Children, 62,* 292–300.

Harry, B. (1997). Applications and misapplications of ecological principles in working with families from diverse cultural backgrounds. In J. L. Paul, M. Churton, W. C. Morse, A. J. Duchnowski, B. Epanchin, P. G. Osnes & R. L. Smith (Eds.), *Special education practice* (pp. 156–170). Pacific Grove, CA: Brooks/Cole.

Individuals with Disabilities Education Act of 1990, 20 U.S.C. § 1400 *et seq*. (1990) (amended 1997).

Kalyanpur, M. (1998). The challenge of cultural blindness: Implications for family-focused service delivery. *Journal of Child and Family Studies, 7,* 317–332.

Kalyanpur, M., Harry, B., & Skrtic, T. (2000). Equity and advocacy expectations of culturally diverse families' participation in special education. *International Journal of Disability Development and Education, 47,* 119–136.

Kalyanpur, M., & Rao, S. S. (1991). Empowering low-income black families of handicapped children. *The American Journal of Orthopsychiatry, 61,* 523–532.

Kleinman, A., Wang, W. Z., Li, S. C., Cheng, X. M., Dai, X. Y., Li, K. T., et al. (1995). The social course of epilepsy: Chronic illness as social experience in interior China. *Social Science & Medicine, 40,* 1319–1330.

Link, B. G., Cullen, F. T., Struening, E., Shrout, P. E., & Dohrenwend, B. P. (1989). A modified labeling theory approach to mental disorders: An empirical assessment. *American Sociological Review, 54,* 400–423.

Link, B. G., & Phelan, J. C. (2001a). Conceptualizing stigma. In K. S. Cook & J. Hagan (Eds.), *Annual review of sociology* (pp. 363–385). Palo Alto, CA: Annual Reviews.

Link, B. G., & Phelan, J. C. (2001b). *On stigma and its public health implications*. Retrieved December 20, 2002, from http://www.stigmaconference.nih.gov/FinalLinkPaper.html

Moore, K. A., & Redd, Z. (2002). *Children in poverty: Trends, consequences, and policy options* (Research Brief No. 2002-54). Washington, DC: Child Trends.

Polakow, V. (1993). *Lives on the edge: Single mothers and their children in the other America*. Chicago: University of Chicago Press.

Seligman, M., & Darling, R. B. (1997). *Ordinary families, special children: A systems approach to childhood disability* (2nd ed.). New York: Guilford Press.

Skinner, D., Bailey, D. B., Correa, V., & Rodriguez, P. (1999). Narrating self and disability: Latino mothers' construction of identities vis-á-vis their child with special needs. *Exceptional Children, 65*, 481–495.

Sloan, V. J., Jason, L. A., & Addlesperger, E. (1996). Social networks among inner-city minority women. *Education, 117,* 194–200.

Sparrow, S. S., Balla, D. A., & Cicchetti, D. (1985). *Vineland adaptive behavior scales.* Circle Pines, MN: American Guidance Service.

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research techniques and procedures for developing grounded theory*. Thousand Oaks, CA: Sage.

Susman, J. (1994). Disability, stigma, and deviance. *Social Science & Medicine, 38,* 15–22.

Therrien, M., & Ramirez, R. R. (2001). *The Hispanic population in the United States: March 2000, current population reports* (No. P20-535). Washington, DC: U.S. Census Bureau.

Thorp, E. K. (1997). Increasing opportunities for partnership with culturally and linguistically diverse families. *Intervention in School and Clinic, 32,* 261–269.

U.S. Census Bureau. (2003). *United States Department of Commerce news*. Retrieved January 26, 2003, from http://www.census.gov/Press-Release/www/2003/cb03-16.html

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U.S. Department of Health and Human Services. (2001). *Mental health: Culture, race, and ethnicity—A supplement to mental health: A report of the surgeon general*. Rockville, MD: U. S. Department of Health and Human Services, Public Health Service, Office of the Surgeon General.

Villarruel, F. A., Walker, N. E., & Minifee, P. Rivera-Vasques, Peterson, S., & Perry, K. (2002). *¿Dónde está la justicia? A call to action on behalf of Latino and Latina youth in the U. S. justice system*. Retrieved October 3, 2002, from http://www.buildingblocksforyouth.org/Full%20Report%20English.pdf

Villenas, S. (2001). Latina mothers and small-town racisms: Creating narratives of dignity and moral education. *Anthropology & Education Quarterly, 32*, 3–28.

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