

# Service Utilization Patterns of Adults with Intellectual Disabilities: A Comparison of Puerto Rican and Non-Latino White Families

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**ABSTRACT.** The increasing ethnic diversity in the U.S. population raises important challenges for community service systems. Little is known about the extent to which service systems meet the needs of different communities of color. This paper examines service utilization and unmet needs of Puerto Rican adults with intellectual disabilities (ID) in comparison to non-Latino white adults with ID to understand better the experiences of midlife and aging families from diverse backgrounds who have entered the service system. In addition, we examine the relationship of maternal support groups to service utilization and unmet service needs. We hypothesize that support groups would be an important resource for Puerto Rican moth-

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ers of adults with ID in facilitating greater use of formal services and decreasing the level of unmet service needs for their son or daughter with ID. Findings indicate that Puerto Rican adults with ID in this study had more severe impairments, received a comparable number of services, and had higher unmet service needs than non-Latino white adults with ID. In the multivariate analysis we examined factors that contribute to service utilization and unmet need for each group. We found that maternal support group participation was a significant predictor of greater service utilization and lower unmet need for Puerto Rican adults with ID, but not for non-Latino whites. These findings suggest that offering caregiver support groups may be a culturally relevant way for service systems to reach out to Puerto Rican families. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <getinfo@haworthpressinc.com> Website: <<http://www.HaworthPress.com>> © 2002 by The Haworth Press, Inc. All rights reserved.]

**KEYWORDS.** Aging, disability, caregiving, culture, Latino

The focus of this paper is on service utilization patterns of Puerto Rican adults with intellectual disabilities (ID) in comparison to non-Latino white adults with ID, as reported by their mid-life and aging mothers. Included in this paper is a comparison of how many and what services are used and needed by each group. In addition, this study attempts to understand the factors that contribute to service utilization, as well as the factors that contribute to unmet needs of Puerto Ricans as compared to non-Latino whites with ID. Puerto Ricans are members of a Latino sub-group who have characteristics that are unique from and similar to other Latino groups. Because research is sparse on Puerto Ricans as a sub-group, we will discuss Puerto Ricans in the context of the literature on the larger Latino group.

Understanding the needs of adults with ID and their parents who are from different ethnic and cultural groups is critical given the increasing ethnic diversity in the United States. Based on prevalence rates of persons with developmental disabilities among different ethnic groups (Fujiura & Yamiki, 1997) and recent demographic trends, Magaña (2000) estimates that there will be more than 720,000 African American and more than 795,000 Latinos with developmental disabilities in the year 2035. These estimates do not reflect the numbers of persons with developmental disabilities from other ethnic backgrounds, which are no doubt substantial as

well. There is rapidly growing interest in cultural competence among service agencies across many fields (Barrio, 2000; Robinson & Rathbone, 1999; Switzer, Scholle, Johnson, & Kelleher, 1998). However, we know very little about utilization of services by persons with ID of different ethnic groups. Are they using services that are currently offered? What are the barriers to service utilization? Are there different services that should be offered to meet the needs of different groups?

Research on service utilization by Latino families with a member with ID is extremely limited. In a study about awareness, use and satisfaction with services, Bailey, Skinner, Rodriguez, Gut, and Correa (1999) found that Puerto Rican and Mexican-American parents of young children with disabilities were generally less satisfied with services received than similar samples of dominant culture families. Although family characteristics such as English proficiency were not found to be related to satisfaction in their statistical analysis, characteristics of the agency such as lack of Spanish language materials and personnel were cited by parents as reasons for their dissatisfaction (Bailey, Skinner et al., 1999). In another analysis that focused on needs and supports within the same sample, Bailey, Skinner, Correa et al. (1999) found that Latino families reported a higher overall level of service need than families in prior research on dominant culture families. In a study comparing Latino families and non-Latino white families with a child with ID, Heller, Markwardt, Rowitz, and Farber (1994) found that Latino families were more likely to report difficulties with the service system. Specifically, they expressed more difficulty finding information on their child's development and participating in parent groups. These investigators attribute the difficulties to language barriers and discrimination against persons of color.

Low rate of service utilization has been a frequent subject of extant literature on Latinos and other ethnic groups (McCallion, Janicki, & Grant-Griffin, 1997; Purdy & Arguello, 1992; Rogler, Malgady, & Rodriguez, 1989; Vega, Kolody, Aguilar-Gaxiola, & Catalano, 1999). In fact, in the ID service system in Massachusetts, the state in which the current research was carried out, low service utilization among Latinos has been recognized as a problem. In an evaluation of service utilization in Springfield, Massachusetts, it was found that although 17% of the Springfield population are Latino (the majority of whom are Puerto Rican), only 3% of the population served by the Department of Mental Retardation in Springfield are Latino (Rodriguez, 1994). McCallion et al. (1997) conducted a qualitative study of families from different ethnic and cultural groups who have an adult child with ID. They attribute low service utilization to: (1) cultural beliefs and practices (i.e., preferring family to provide

care, not wanting to discuss problems with strangers, not viewing services as part of cultural traditions); (2) low socio-economic status, and (3) low level of cultural competence of the service system resulting in discrimination, services designed for mainstream groups, and poor information about services provided to members of various cultural groups.

Consistent with the first point made by McCallion et al. (1997) with respect to cultural beliefs and practices, low service utilization has been attributed to a Latino cultural value known as "familism." Familism is characterized in the service utilization literature as commitment to family caregiving, although it encompasses a much broader concept of interdependence among family members including solidarity, reciprocity and loyalty (see Marin & Marin, 1991 and Sanchez, Perez-Prado, & Cadavid, 1998 for more details on Latino cultural values). This value has been credited alternatively with either meeting the needs of Latinos or serving as a barrier to receiving needed services (Purdy & Arguello, 1992; Rogler et al., 1989). The former point has been termed the "alternative resource theory," i.e., researchers theorize that group needs are being met through the alternative resource of family rather than the formal service system (Rogler et al., 1989). Purdy and Arguello (1992), in support of the latter point, argue that the family serves as a barrier to elderly Latinos' use of needed services. These authors theorize that family members who are trying to live up to the cultural expectation that the elder must be cared for within and by the family may prevent the Latino elders from knowing about needed services that are available. In contrast, Delgado and Tennstedt (1997) studied Puerto Rican elders and their caregivers in the Northeast and found that many Puerto Rican elders lived alone and the number of family caregivers was limited. These investigators attribute the limited availability of family caregivers to economic constraints and migration patterns of Puerto Ricans who live in the Northeast. As Puerto Rican elders migrated from Puerto Rico to different cities in the Northeast looking for better economic opportunities, their family support systems may have eroded little by little with each move. Despite limited family involvement, service utilization was low as well. Nevertheless, family caregivers reported that arranging services was one of their most frequent functions (Delgado & Tennstedt, 1997).

Lack of knowledge about services has been cited in several studies as an important reason for underutilization of services among Latinos (Bailey, Skinner et al., 1999; Delgado & Tennstedt, 1997; Starrett, Mindel, & Wright, 1983; Vega et al., 1999). Another cultural factor that may contribute to lack of knowledge for Latinos is the cultural value known as "respeto" which includes a strong recognition of status of and

deference to people who are older, male, of higher class status, and in positions of authority (Marin & Marin, 1991; Sanchez et al., 1998). According to Sanchez et al. (1998), *respeto* is one of the most significant elements of Puerto Rican culture because it provides a context in which individuals acknowledge the social worthiness of others. These authors further state, “*Respeto* would forbid the open questioning of someone’s behavior or ideological stance based . . . on (their) positional relationship” (Sanchez et al., 1998, p. 19). In this context, there is a certain amount of trust extended to persons in authority such as service providers. This may mean that individuals adhering to the cultural value of *respeto* are entrusting the service provider to offer all possible services. In contrast, in the context of service systems in United States, the expectation is that individuals will be assertive, seek out needed services, and advocate for themselves when necessary. Latino individuals who adhere to the cultural value of *respeto* may not be familiar with this way of accessing and advocating for services and may be less likely to ask for services that are not offered.

Perhaps the most important barrier to knowledge about services is that many agencies within the service system do not provide services in a culturally relevant way (Barrio, 2000; McCallion et al., 1997). For example, outreach and education to the Latino communities may be limited, agencies may not take into account important cultural values such as familism and *respeto*, and access barriers such as language, transportation, and child care are not addressed.

A study that evaluated the provision of parent training for Latino families with a child with ID found that a program specifically designed for Latinos had high levels of utilization, contrary to previous reports of underutilization of this population (Prieto-Bayard & Baker, 1986). The participants were 20 Spanish-speaking families recruited by regional center staff in California. Researchers found that 78% of the families who began the 10 week training program completed it. The investigators attribute the high rates of participation to collaboration with a service organization known to the families, extensive outreach, and removal of access barriers, i.e., a more culturally competent model. Specifically, the program was based in the community, held in the evening, conducted in Spanish and child care was provided (Prieto-Bayard & Baker, 1986).

Although Latinos experience a number of unique challenges in accessing services, they share commonalities with other ethnic groups including whites. Factors found to contribute to higher service utilization across ethnicities for older persons include living alone, and having higher levels of disabilities or impairment (Burnette & Mui, 1995; Mui & Burnette, 1994; Tennstedt & Chang, 1998). In a study of the service needs of aging fami-

lies of adults with ID, Smith (1997) found that predictors of service use were lower income, female gender of the person with ID, greater need for care, higher levels of maternal burden and poorer maternal health. Smith (1997) also examined unmet service needs and found that families had greater unmet needs when mothers were married, reported higher levels of burden, and received less help from other children.

In this paper, we examined the contribution of characteristics of the adult with ID and characteristics of the mother to the number of services received by the adult and the number of unmet needs perceived by the mother. In addition, we explored a potentially important factor, namely maternal participation in a support group. We specifically examined this resource because the Department of Mental Retardation (DMR) and its contracting agencies have established support groups as a way of reaching out to Latino parents. We hypothesized that the support groups were an important resource for the Puerto Rican mothers in our sample that may facilitate greater use of formal services, and diminish the level of unmet service needs.

Support groups have been described as a culturally relevant way to provide services to Latino families (Blue-Banning, Turnbull, & Pereira, 2000; Shapiro & Simonsen, 1994; Simoni & Perez, 1995). Support groups have been shown to be beneficial for people from all backgrounds who are experiencing many different problems, illnesses and caregiving situations. Support groups help individuals to become educated about the issue, learn that others also confront similar problems, and gain additional support from the participants. These benefits are especially important to Latinos and people of color because they can be isolated not only as individuals dealing with a problem, but also as minorities in the dominant culture. Support groups provide additional relevance for Latinos because there can be a familial component to the social interaction (i.e., support group members become supportive of each other in ways similar to family members), and can foster interdependence, which is a part of a collectivist world view compatible with Latino culture. Another important aspect for Latinos is that support groups can empower participants by educating them about the service system and about the necessary skills to obtain services, while taking into account cultural values such as familism and respeto.

The research questions addressed in this analysis included: (1) What are the most frequently received services and the greatest unmet service needs of Puerto Rican adults with ID in comparison to non-Latino white adults with ID? (2) What are the differences and similarities in predictors of service utilization and unmet service need between the two groups? and

(3) What are the barriers to receiving needed services for Puerto Rican adults with ID as reported by their mid-life and aging mothers?

## ***METHOD***

### ***Sample***

The Puerto Rican sample included in this analysis consists of 66 Puerto Rican families living in Massachusetts. Participants met three criteria: the mother was the main caregiver for a son or daughter with ID, the son or daughter lived at home, and the mother and/or son/daughter were of Puerto Rican descent. Both Spanish-speaking and English-speaking families were eligible to participate in the study; all participants except one chose to have the interview conducted in Spanish. The original Puerto Rican sample consisted of 72 families. However, because the focus of this paper is on adult services, those cases in which the son or daughter with ID was under 18 years of age were excluded.

Puerto Rican families were recruited with the help of personnel from 14 area offices of the Massachusetts Department of Mental Retardation (DMR) and community organizations that serve Latino families who have a family member with an intellectual disability. In addition, eight families were referred by participating sample members. The service providers were asked to refer all families who met the three criteria noted above. Service providers presented information written in Spanish or English to the families and reviewed it with them. They then asked families if they would be interested in being contacted by the study staff. There was a 97% response rate of those families who were approached about the study.

The non-Latino white sample consists of a sub-sample of families from a longitudinal study of families in Wisconsin and Massachusetts who met two criteria at the beginning of the study in 1988: the mother was age 55 or older and had a son or daughter with ID living at home (see Seltzer & Krauss, 1989, 1994, for study methodology). The primary method of recruitment was via the formal service system (e.g., DMR, Wisconsin Department of Health and Family Services), although snowball sampling was also used. Data were collected 8 times (every 18 months). The sample for the present analysis consists of persons with ID who lived with their mothers in Massachusetts at the time of the second point (Time 2) of data collection. Only those mothers who lived in Massachusetts were selected because services would be more comparable to the Massachusetts Puerto Rican sample. Time 2 was selected because we had comparable data from

both studies at that time point. We included in this analysis 179 of the original 226 Massachusetts mothers, all those whose son or daughter continued to live at home at Time 2. Of the others, 10 persons with ID had moved out of the home prior to Time 2, 29 were not included due to inability to locate or mother refusal, 5 were not included due to the death of the son or daughter with ID, and 3 did not have complete data on services.

Table 1 shows a comparison of the two groups on demographic characteristics. Non-Latino white mothers were significantly older, had higher education levels, were in better health and were more likely to be married than the Puerto Rican mothers. Non-Latino white adults with ID were significantly older, had less severe ID and higher levels of functioning than the Puerto Rican adults with ID. In addition, non-Latino white adults with ID exhibited fewer maladaptive behaviors.

### *Measures*

Maternal characteristics included mother's age, marital status, years of education, and health status. Marital status was coded 1 for married, and 0 for widowed, divorced, separated or single. Education level included 7 categories from less than high school to completed graduate school. Mother's health status was measured by a question taken from the Older Americans' Resources and Services Multidimensional Functional Assessment, which asks the mother to rate her own health from excellent (4) to poor (1). The criterion-related validity of this item with a physical examination was reported to be .70 (Multidimensional Functional Assessment Manual, 1978).

Characteristics of the son or daughter with ID included level of functional abilities and number of maladaptive behaviors. Level of functional abilities were measured using the revised Barthel Index (Mahoney & Barthel, 1965), a 31-point scale of instrumental and functional skills, with each item scored on a 4-point scale of independence. Higher scores denote more independence. Number of maladaptive behaviors were measured by a scale from the ICAP (Inventory for Clients in Agency Planning; Bruininks et al., 1986). There were eight items for which the mother was asked whether her son or daughter exhibited the maladaptive behavior. The ICAP score was the number of maladaptive behaviors reported by the mother.

For the variable of maternal participation in a support group, mothers in both studies were asked, "Do you belong to a parent support group?" No was coded 0 and yes was coded 1.

TABLE 1. Differences in Maternal and Child Characteristics

	Puerto Rican (N = 66)	Non-Latino white (N = 179)	Test
<b>Maternal Characteristics</b>			
Mean age	57.4 (8.8)	68.1 (6.5)	$t = -9.0^{***}$
Percent with high school education or higher	21.2	79.9	$\chi^2 = 72.1^{***}$
Percent in good or excellent health	24.2	72.1	$\chi^2 = 45.7^{***}$
Percent married	39.4	53.6	$\chi^2 = 3.9^*$
<b>Adult with ID Characteristics</b>			
Percent female	54.5	48.0	$\chi^2 = .8$
Mean age	30.1 (8.1)	36.2 (7.1)	$t = -5.7^{***}$
Percent with severe or profound ID	50.8	17.3	$\chi^2 = 26.7^{***}$
Mean functional level	52.1 (13.0)	62.0 (9.9)	$t = -5.6^{***}$
Mean number of maladaptive behaviors	2.8 (2.1)	1.8 (1.8)	$t = 3.4^{**}$

Standard deviation in parentheses  
\*  $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$ .

Services were measured using a list of 14 services that are typically received by persons with ID. Mothers were asked if their son or daughter received the service, and if yes, they were asked how satisfied they were with the service. If the service was not received, mothers were asked if it was needed. For the Puerto Rican study, mothers were also asked why the service was not received (i.e., barriers to service access). The number of services received by the adult with ID and the number of unmet services needs were totaled. Thirteen services were included in this analysis: financial assistance, case management, transportation, respite, social and recreational services, psychological services, physical therapy, speech therapy, occupational therapy, legal services, self-care services, nursing and nutritional services. Day or vocational programs were not included in the count of number of services because this service was measured differently between the two groups. However, data were collected on whether the adult with ID was in a day program versus at home during the day.

### *Data Collection Procedures*

For both samples, mothers participated in a structured interview in their homes. The non-Latino white mothers also completed self-administered standardized assessments. For the Puerto Rican sample, interviews were conducted by bilingual/bicultural interviewers and all items were read to the mothers (because some mothers were not able to read or felt less comfortable with a reading and writing component). Measures were translated using the back-translation method (Kurtines & Szapocznik, 1995).

### *Analysis*

Chi squares were conducted to determine differences in categorical demographic characteristics between each group, and to determine differences in service receipt, satisfaction and unmet need of each service between each group. T-tests were conducted to determine mean differences in continuous demographic characteristics. Separate multiple regressions were conducted for each group to determine the predictors of number of services received and number of unmet service needs. To test the equality of the two regression equations (i.e., to determine whether to reject the null hypothesis that there are no differences in predictors between the two groups), an F-statistic was used as described by Crown (1998). An alpha level of .05 was used for all statistical tests. In addition to the comparative bivariate and multivariate analyses, descriptive data are presented on the Puerto Rican mothers' perception of barriers to service utilization.

## **RESULTS**

### ***Differences in Service Utilization Between Puerto Rican and Non-Latino White Adults with ID***

For the first research question, we asked, "what are the most frequently received and the greatest unmet service needs for Puerto Rican adults with ID in comparison to non-Latino white adults?" With respect to services received, Table 2 shows that the top five services used by both groups of mothers were: financial assistance, social work/case-management, transportation, respite, and social/recreational services. Puerto Ricans with ID received significantly more physical therapy, occupational therapy, nursing, personal care, and legal services, while non-Latino white persons received significantly more transportation and social/recreational services. Both groups were equally satisfied with services, with the exception of speech therapy, for non-Latino white mothers reported less satisfaction.

There was no significant difference between the two groups on the *total number of services received* (Puerto Rican  $M = 4.5$ ,  $SD = 2.0$ , non-Latino white  $M = 4.2$ ,  $SD = 1.7$ )  $t(245) = 1.3$ . However, because there are a number of significant differences between the two groups such as higher impairment levels of the Puerto Rican adults with ID, and differences in socio-demographic characteristics of the mothers (see Table 1), it is important to take these differences into account in assessing service utilization. When we conducted ANCOVAs controlling for these differences (number of behavior problems, functional level, maternal education level, maternal health, age and marital status), we found that the adjusted mean number of services used by non-Latino whites was 4.4 ( $SE = .14$ ) and the adjusted mean for Puerto Ricans was 3.8 ( $SE = .27$ ),  $F(1, 245) = 3.9$ ,  $p < .05$ . This indicates that after controlling for these factors, the service utilization rate of non-Latino whites was significantly higher.

Another important service for persons with ID that is not listed on Table 2 is the day or vocational program, which can include a day activity center, sheltered workshop, supported employment, independent employment, or school (for those 22 and under). While we did not have consistent information across the two groups about type of day programs, we asked a common question about what the adults with ID did during the day. From this, we were able to determine the number of adults who are in some type of day program versus the number of adults who stay at home. Non-Latino white persons with ID were significantly more likely to be in a day program (89.9%) than Puerto Rican adults (59.1%)  $\chi^2(1, N = 245) = 30.6$ ,  $p > .001$ .

An important variable in our analysis is parent support group participation. Puerto Rican mothers were significantly more likely to participate in a parent support group (43.9%) than non-Latino white mothers (19.6%)  $\chi^2(1, N = 245) = 14.9$ ,  $p > .001$ .

Table 2 further shows that Puerto Rican mothers reported significantly more *unmet need* for every service except financial assistance, social work, and respite, than did the non-Latino white mothers. Despite differences in the number of unmet needs, the types of services for which there was highest unmet need were similar for both groups. For each group, the five greatest unmet service needs were social and recreational activities, speech therapy, occupational therapy, respite, and physical therapy. The order of priority was slightly different for each group; for example, as shown in Table 2, the most needed service reported by Puerto Rican mothers was social and recreational services, and the most needed service reported by non-Latino white mothers was speech therapy.

TABLE 2. Comparison of Services Received, Service Satisfaction and Services Needed (Puerto Rican N = 66, Non Latino White N = 179)

Service	Services Received <sup>1</sup>		Service Satisfaction <sup>2</sup>		Unmet Service Need <sup>3</sup>	
	Puerto Rican	White	Puerto Rican	White	Puerto Rican	White
Financial Assistance (SSI)	92.4	91.6	62.3	51.8	3.0	1.1
Social Worker/Case Manager	83.3	79.3	64.2	66.4	10.6	7.8
Transportation	59.1	79.4*	74.4	77.0	19.7	7.3**
Respite	45.5	41.9	82.8	79.4	28.8	25.7
Social/Recreational Services	31.8	58.7***	71.4	63.2	53.0	24.6***
Psychological Services	30.3	21.2	55.0	52.6	21.2	10.6*
Physical Therapy	24.2	8.4**	56.3	73.3	25.8	12.3*
Personal Care Assistant	25.8	6.7***	77.8	58.3	18.2	5.6**
Occupational Therapy	22.7	10.1*	73.3	58.8	39.4	11.7***
Nursing	15.2	6.1*	90.0	90.9	12.1	2.2**
Speech Therapy	7.6	8.9	100.0	31.3**	43.9	27.4***
Legal Services	10.6	2.8*	85.7	60.0	19.7	8.9*
Nutritional Services	1.5	3.9	100.0	71.4	19.7	7.8**

<sup>1</sup> Percent receiving service

<sup>2</sup> Of those receiving service, percent reporting that they were very satisfied

<sup>3</sup> Percent who are not receiving and need service

\*p < .05. \*\*p < .01. \*\*\* p < .001

With respect to the total number of unmet service needs, Puerto Rican mothers reported significantly more unmet service needs ( $M = 3.2$ ,  $SD = 2.1$ ) than non-Latino white mothers ( $M = 1.5$ ,  $SD = 1.5$ )  $t(245) = 5.8$ ,  $p < .001$ . Adjusting for the demographic and functional differences between the two groups as we did with number of service used, the difference in unmet service needs between the two groups was not as great, but still significant: Puerto Rican  $M = 2.8$ ,  $SE = .27$ , non-Latino white  $M = 1.6$ ,  $SE = .14$ ,  $F(1, 245) = 11.5$ ,  $p = .001$ .

In sum, there are many similarities across the two groups with respect to service utilization and satisfaction with services. For example, the most frequently used services for each group were similar, and both groups were equally satisfied with services they received. Some differences are that Puerto Rican adults with ID receive more services such as physical and occupational therapies, nursing, and personal care. Non-Latino white adults receive more services related to social and vocational development such as social and recreational activities, day programs and transportation.

For unmet needs, patterns are similar between the two groups, although Puerto Rican mothers report more unmet need overall.

### ***Predictors of Service Utilization and Unmet Service Needs***

Our second question was, “what are the differences and similarities in the predictors of service utilization and unmet service need between the two groups?” A correlation matrix of all study variables used in the analyses is presented in Table 3. The upper diagonal presents the correlations for the non-Latino white families, while the lower diagonal presents the correlations for the Puerto Rican families.

Table 4 shows two multiple regression models (predicting number of services received and number of unmet service needs) for each group. With respect to the predictors of number of services received, there were similarities and differences across the groups. For both groups, lower functional level of the person with ID was predictive of more services received. More maladaptive behaviors was related to more services for non-Latino white adults with ID, but not for Puerto Rican adults. There was a weak trend ( $p < .10$ ) for older non-Latino white mothers to report that their son or daughter received fewer services. Consistent with our hypothesis, participation in a support group was predictive of more services received for Puerto Rican mothers, but not for non-Latino white mothers.

With respect to unmet service needs, for the non-Latino white sample, the most significant predictor of higher unmet need was poor maternal health. There were weak effects for non-Latino white adults with lower functional levels and more maladaptive behaviors to have higher unmet need. For Puerto Rican mothers, those who were married, and whose son or daughter had more maladaptive behaviors were more likely to report higher unmet needs. Again as hypothesized, Puerto Rican mothers who participated in support groups reported lower unmet service needs for their sons or daughters.

To test whether the predictors of the number of services received and the number of unmet service needs differed significantly between Puerto Rican families and non-Latino white families, an F statistic was used taking into account the sum of squared errors of a regression model with combined samples, and the sum of squared errors of separate regression models for each group (Crown, 1998). The two regression models (Puerto Rican families and non-Latino white families) predicting the number of services received were found to be significantly different from each other,  $F(8, 229) = 2.14, p < .05$ . Likewise, the two regression models for the number of unmet services were also found to be significantly different, F

TABLE 3. Correlations Among Study Variables

Correlations	1.	2.	3.	4.	5.	6.	7.	8.	9.
1. Number of services received	1.000	-.19*	-.16*	.06	.01	-.27***	.35***	-.10	.05
2. Number of unmet services	-.47***	1.000	-.04	-.08	-.02	-.18*	.18*	-.22**	-.17*
3. Maternal age	.03	-.01	1.000	-.31***	-.00	.06	-.14	-.14	.13
4. Mothers currently married	-.25*	.29*	-.36**	1.000	.07	-.02	-.02	.11	.12
5. Mothers' education level	.09	.13	-.17	.22	1.000	.11	.06	.23**	-.17*
6. Functional level of person with ID	-.34**	.03	-.19	.27*	.01	1.000	-.16*	.06	.09
7. Number of maladaptive behaviors of person with ID	.18	.21	-.20	-.08	.16	-.03	1.000	-.07	-.02
8. Mothers' health status	-.10	-.04	-.12	-.03	.17	-.10	-.06	1.000	.19*
9. Mothers who belong to a parent support group	.38**	-.23	-.17	-.15	.01	-.14	.26*	-.02	1.000

Puerto Rican correlations on the bottom of the matrix, non-Latino white correlations on the top of the matrix

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$

(8, 229) = 3.84,  $p < .01$ . This analysis indicates that the determinants of Puerto Rican and non-Latino white service utilization and unmet service needs are significantly different from each other.

Because many of the Puerto Rican mothers were receiving services from Latino service organizations who were contracted by DMR, it was possible that the findings regarding the effects of support group participation by Latino mothers were really due to the families' connection to these Latino (presumably culturally competent) organizations. To investigate this possibility, we created a dummy variable for receiving services from contracting Latino agencies ([1],  $N = 34$ ), versus not receiving services from these agencies ([0],  $N = 32$ ). We then conducted t-tests using this new variable, and compared service utilization and unmet service need of those who were receiving services from contracting agencies with those

TABLE 4. Regressions Comparisons of Number of Services Received and Number of Unmet Services

Dependent Variables	Services Received		Unmet Service Needs	
	Puerto Rican (N = 66)	Non-Latino white (N = 179)	Puerto Rican (N = 66)	Non-Latino white (N = 179)
<b>Maternal Characteristics</b>				
age	-.02	-.13	.12	-.05
marital status	-.17	.02	.32*	-.06
education level	.14	.02	.03	.06
health status	-.15	-.11	-.01	-.19*
<b>Son or Daughter with ID Characteristics</b>				
functional level	-.27*	-.22**	-.06	-.14
# of maladaptive behaviors	.05	.29***	.31*	.12
Support Group				
mother belongs to support group	.30*	.11	-.25*	-.11
Adjusted R <sup>2</sup>	.20	.17	.12	.08
F Statistic	3.2**	6.2***	2.3*	3.1**

Note. Standardized betas shown  
\*p < .05. \*\*p < .01. \*\*\*p < .001

who were not. We found no significant differences (data available from the first author) between those who received services from Latino agencies and those who receive services from generic (white) agencies. From this analysis we were able to conclude that receiving services from a Latino agency does not account for the relationship between participation in support groups and service utilization.

### ***Barriers to Receiving Services for Puerto Rican Adults with ID***

For our last question, we examined what the barriers were to receiving needed services for Puerto Rican adults with ID as reported by their aging mothers. If Puerto Rican mothers stated that they did not receive the service, and that the service was needed, we asked why they did not receive the service. Because this question was not asked of the non-Latino white mothers at data collection Time 2, we only present data from Puerto Rican mothers. Table 5 shows the barriers to the five most needed services as re-

ported by the Puerto Rican mothers. Responses fell into six categories: access problems, service was denied or cut, the person with ID was on a waiting list for services, the service was not acceptable to the mother or to her son or daughter, the mother did not know how to access the service, or there was a language or cultural barrier. The most frequently reported category for all five services was that of not knowing how to access the service. Many mothers did report being on a waiting list for the needed service, being denied, having access problems or not accepting the service that was offered. Very few mothers reported not receiving the service because of cultural or language problems.

### DISCUSSION

The increasing ethnic diversity within the U.S. population raises important challenges for the growth of community-based service systems. While many studies have reported that Latinos and other ethnic groups are under-represented in the service systems (e.g., Rogler, Malgady, & Rodriguez, 1989; Starrett, Mindel, & Wright, 1983; Vega, Kolody, Aguilar-Gaxiola, & Catalano, 1999), there is less clarity about why this is so. Some point to the lack of "cultural competence" among providers of services, speculating that if service systems included bilingual and bi-cultural staff, provided information in multiple languages, and/or offered services that were designed within the cultural norms of various groups, service utilization by ethnic groups would increase (Barrio, 2000; McCallion, Janicki, & Grant-Griffin, 1997; Prieto-Bayard & Baker, 1986). Some point to cultural beliefs among different ethnic groups that may temper the propensity to seek needed assistance outside of the family and/or to display the assertiveness that is often required to obtain services (Purdy & Arguello, 1992; Sanchez, Perez-Prado, & Cadavid, 1998).

Most previous studies that document the lower than expected presence of persons of color within formal service systems do so by comparing the proportion of the served population who are persons of color with their prevalence within the general population. The present study, however, offers an opportunity to contrast service utilization patterns between a specific ethnic group—Puerto Rican families of adults with ID—and service utilization patterns of similarly situated white families *within* a publically supported service system. As such, the results of our analyses provide important information about the experiences of families from diverse backgrounds who have entered the service system. And, as noted earlier, many of the Puerto Rican families were served by agencies that were considered

TABLE 5. Reasons for Unmet Services (5 services with the highest unmet need included)

Reason for Unmet Need	1. Access Problems	2. Denied or Cut	3. On Waiting List or Asked for Service	4. Service Not Acceptable to Mother or S/D	5. Doesn't Know How to Access Service	6. Language or Cultural Problem
Type of Service						
Social & recreational activities	11.8%	0%	26.4%	11.8%	50.0%	0%
Speech therapy	3.4%	17.2%	10.4%	0%	62.1%	6.9%
Occupational therapy	14.8%	7.4%	11.1%	0%	59.3%	7.4%
Respite	5.3 %	0%	5.3 %	10.5%	78.9%	0%
Physical therapy	11.8%	11.8%	0%	5.9%	64.6%	5.9%

**Description of reasons for unmet need:**

**1. Access problems:** Service too expensive, inconvenient, not available in area or no transportation

**2. Denied or cut:** Service was requested and denied, or was previously received but cut

**3. On waiting list or asked for service:** Son or daughter is on an official waiting list, or mother requested service

**4. Service not acceptable to mother or s/d:** Either son or daughter refused service, or mother felt it wasn't acceptable according to her standards

**5. Doesn't know how to access service:** Mother doesn't know who to ask, how to access service or whether service is available

**6. Language or cultural problem:** Mother reported a specific problem with language barrier or lack of cultural understanding on the part of the service providers

to be culturally competent, which enhances the significance of our findings.

Three major findings from our analyses warrant comment. First, we found that, compared to white adults with ID, Puerto Rican adults with ID were significantly less likely to receive transportation, social/recreational services, and day program services, but were significantly more likely to receive physical therapy, personal care assistance, nursing services, and legal services. These differences may reflect the greater severity of disability reported by the mothers of the Puerto Rican adults with ID in comparison to their white peers, and may be one indication of the “match” between obvious needs and the services provided. However, we also found that when the differences in the functional characteristics and demographic characteristics that exist between the two groups were taken into account, the average number of services received was slightly lower for the Puerto Rican group than for the white group. And, we found that there was a significantly higher level of unmet service needs for the Puerto Rican adults with ID for virtually all services examined, suggesting that

there is an unaddressed range of services needed by this group of ethnic minority adults with severe disabilities.

Second, we note that for Puerto Rican mothers, participation in a parent support group was predictive of higher levels of service utilization for their adult child with ID. We cannot determine the direction of effects between support group participation and number of services received (based on our cross-sectional data) but these findings suggest the vital role that support groups can play within the service system. Support groups provide an important opportunity for service providers to reach out to parents who may benefit from the emotional support exchanged in such settings and from the opportunity to learn more about available services and supports in the community. They may be especially effective for ethnic minority groups who may be otherwise reluctant to press for more services, either because they do not know about other potentially useful services (consistent with our findings), have less experience or comfort being assertive with service providers, or have less access to the range of resources available to families to help them develop strategies to meet the needs of children with disabilities (i.e., conferences and workshops, online websites, and resource books). The information sharing and emotional solidarity that may develop among the members of the support group may well translate into effective strategies for acquiring a wider range of needed services.

Third, we found that the level of unmet service needs among Puerto Rican families (which was significantly higher in this group compared to white families) was associated with the mother's marital status (married mothers reported higher levels of unmet need for their children), the child's maladaptive behaviors (adult children with higher levels of maladaptive behavior had more unmet service needs), and maternal participation in support groups (those not in support groups had higher levels of unmet needs for their children). These findings invite some speculation about how service providers should approach Puerto Rican families of adults with ID. On the one hand, being married may be viewed as a positive resource for Puerto Rican women who are active caregivers for adult children with ID, insofar as the responsibility of caregiving presumably may be shared with another involved family member. However, we found in a previous study that for Puerto Rican and Cuban American mothers, that being married is also related to more caregiving burden (Magaña, Seltzer, Krauss, Rubert, & Szapocznik, in press). Burden may be increased for married mothers of adults with ID in part due to traditional gender roles in some Latino households, and in part due to our current finding that being married is also associated with more limited access to

needed services. It may be particularly important for service providers to probe explicitly about unmet service needs when working with married Puerto Rican mothers.

Interestingly, higher levels of maladaptive behavior were predictive of greater utilization of services among white families, but among Puerto Rican families, it was predictive of higher levels of unmet needs. We did not ask whether families were receiving professional assistance in parental behavioral management strategies. It may be that this service is less available for Puerto Rican families. Providing this service in Spanish and in a culturally sensitive way may facilitate increased access to needed services for those families with an adult child with ID who has maladaptive behaviors.

Finally, participating in a support group by Puerto Rican mothers was predictive of lower levels of unmet need among their adult children with ID. As noted above, encouragement of support group participation may be a cost-effective strategy for establishing greater linkages between community-based service agencies and minority populations.

Limitations of this study include the fact that the small size of the Puerto Rican sample limited the number of variables and types of analysis we could use, and may not have allowed for detection of all relationships; the convenience samples used in these analyses may not be representative of all non-Latino white and Puerto Rican families of adults with ID in Massachusetts; and because this was a cross sectional analysis, the direction of relationships could not be determined. Nevertheless, this study makes a contribution to the small but growing body of literature about Latino families with an adult child with ID.

In conclusion, this study provides a unique opportunity to understand better the experiences of Puerto Rican families who are connected to a service system. It is important that researchers and practitioners continue to probe the reasons why families of color are under-represented in publicly supported service systems, but it is also critical to examine how well their needs are met once they are *in* a service system. The results from the present study identify relative parity (in contrast to non-Latino white families) in the number of services received, but striking differences in the specific types of services received, and in the level of unmet service needs. We also identified a powerful tool that may be effective in addressing these differences, namely participation in parent support groups. These results warrant replication in other studies, but begin to provide some guidance to professionals regarding potentially effective strategies for serving our increasingly diverse citizenry.

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