ABSTRACT (249 words)
Objective: To identify both the needs that may distinguish Latino from Anglo American parents of disabled children and the needs that may transcend ethnicity.
Design: A multi-method ethnography using data from both semi-structured protocols and structured interviews. Protocol interview texts were analyzed with a variant of schema analysis. Structured interview data were analyzed with correspondence analysis and ordinary least squares regression.
Participants: The primary caregiver from eighty families of children with disabilities (Latino n=40, Anglo n=40) selected from the State of Connecticut Title V Program, administered through the Yale Center for Children with Special Health Care Needs, matched by set on children’s age and the type and severity of disability.
Main Outcome Measures: The number and kind of unmet needs reported by primary caregivers.
Results: Regression analysis revealed that 57% of the variation in the number of unmet needs (standard error of the estimate = 1.1) was explained by whether or not the disability entailed multiple organ systems (effect=1.1, p<.001), whether or not an Anglo-American caregiver was a single parent (effect=3.4, p<.001), whether or not the caregiver was Latino (effect=4.6, p<.001), and variation in the income of Anglo American caregivers (effect=.12; p<.001). Correspondence analysis revealed two sets of unmet needs among families who reported several kinds of unmet needs, which corresponded with ethnic differences.
Conclusions: Effective delivery of health care requires us to identify cultural clashes in assumptions about the proper role of providers and, where appropriate, to help patients advocate and manage their child’s health care delivery.
Designing and Delivering Culturally Competent Health Care: A Study of the Unmet Needs of Latino and Anglo Families of Children with Disabilities

Introduction
This study seeks to identify both the needs that may distinguish Latino from Anglo American parents of disabled children and the needs that may transcend ethnicity. Latino children with disabilities experience significantly higher risks for poor health and development than their Anglo American peers. Latinos have lower incomes, less education, and are less likely to speak English, have health insurance, and use and participate in services and parent programs than Anglo-American counterparts. Previous research on the perceived needs of Latino families of children with disabilities indicates that Latino families need help in a greater variety of ways than Anglo American and African American families. The most commonly reported such needs are information about the child’s condition, available services, and strategies for interacting with their child. However, single-parent status and the severity of a child’s disability predicted an increased number of reported needs among Latinos living in the United States and in Puerto Rico. Latino families have been found to be less likely than Anglo American families to cite needs for respite, day care, and home health aides, and more likely than Anglo Americans to report need for information.

The extent to which these findings apply generally remains unclear, as does whether ethnic differences in needs apply to a more comprehensive set of needs for equipment, changes in education program, a change in the therapy program, a support group, a recreation program, or a social worker to help manage their child’s care. Do ethnic differences appear when we ask caregivers to tell us whether or not they feel supported, and whether or not their child’s needs were adequately met? Do ethnic difference also appear when parents are asked whether they feel able to advocate for their child effectively, in control of their child’s health care needs, or grateful, happy, frustrated, or satisfied with the care their child received? Does single-parent status or the severity of a child’s disability exhibit different effects for parents of different ethnic groups? What about whether or not a caregiver must also work? Does the level of education influence unmet needs? What specific cultural norms and behavioral patterns produce differences in needs that correspond with ethnicity?

Methods
To answer these questions, we carried out a multi-method ethnographic study that entailed 9 months of participant-observation of Latino and non-Latino families, semi-structured protocols, and structured interviews carried out in the first language of the research participants. Participants consisted of a convenience sample of 40 Latino and 40 non-Latino (Anglo-American) families chosen from the State of Connecticut Title V Program, which is administered through the Yale Center for Children with Special Health Care Needs (CSHCN). In all cases, the respondent to the structured interview was the mother (the primary caregiver) of the child. All Latino families reported that they spoke Spanish as their first language. Only 5% of Latino participants spoke some English as a second language. All but nine (22.5%) of the Latino participants were born outside of the continental United States. The families had spent an average of 7.9 years in the United States. Ten (25%) of the children in the study were born in Puerto Rico.

We measured the level of disability severity with the KIDDaat©, a clinical tool used at the Yale Center for CSHCN and in the State of Connecticut Title V Program. The KIDDaat© uses
frequency counts by clinicians of types of body systems involved (e.g., central nervous system, cardiovascular, musculoskeletal, dental/oromaxifacial, renal/urological), the number of conditions present (e.g., speech/language disorder, upper motor neuron disorder, mental retardation, peripheral neuropathy), and the number of special types of equipment used by a particular child (i.e., hearing aid, orthotic devices, crutches, wheelchair, adaptive seating device). Twenty-nine of the Latino children had a diagnosis of cerebral palsy, as compared to 30 children with cerebral palsy from Anglo-American families. The remaining children had a diagnosis of developmental delay. The average age of children was 8 years of age (SD = 5) and the mean KIDDAat Score was 10 (SD = 4). Two-sample t-tests for the difference between Latino and Anglo American families yielded a p = .691 for KIDDAat Score and a p = .739 for age of child. These high probabilities are consistent with only chance differences between Latino and Anglo American participants in the age of children and the severity of the child’s disability.

A two-sample t-test for the difference in income between Latino and Anglo American participants, however, yielded a p < .001. The average income of the participant families was $19,000, but Anglo American families averaged $22,990 (SD = $9,805) and Latino families averaged only $14,705 (SD = $7,296). Whereas 28% of Latino caregivers had studied beyond high school, 95% of Anglo American caregivers had acquired some post-high school education (Fisher’s Exact Test, p < .001). Sixty-six percent of all caregivers reported not working at the time of our study. But whereas 78% of Latino caregivers reported not working, only 55% of Anglo American caregivers reported not working (Fisher’s Exact Test, p = .058). Whereas 52% of Latino caregivers reported a single parent household, only 10% of Anglo American caregivers reported single parent status (Fisher’s Exact Test, p < .001).

Data from participant-observation and the semistructured protocols elicited information about family needs, family coping styles and family-professional interaction styles. We analyzed the resulting text data using theme content analysis. Findings from this first phase of research made it possible to construct an efficient and comprehensive structured interview bearing on research participants’ unmet needs concerning: (1) equipment, (2) change in education program, (3) a daycare program, (4) a home health aide, (5) respite care, (6) information, (7) a change in the therapy program, (8) a support group, (9) a recreation program, and (11) a social worker to help manage their child’s care. We also asked caregivers to tell us whether or not they felt (10) supported, (11) that their child’s needs were adequately met, (12) able to advocate for their child effectively, (13) in control of their child’s health care needs, and (14) grateful, (15) happy, (16) frustrated, or (17) satisfied with the care their child received. We used binary (yes, 1; no, 0) codes for all variables.

Our regression model for number of unmet needs will include 12 variables, seven main effects (Latino or Anglo; severe disability or not; single-parent or not; whether or not Latino caregivers spoke English, post-secondary schooling or not, working or not, and income) and five interaction effects (ethnicity interactions with single parent status, income, post-secondary schooling, working, and disability severity). With a sample size of 80 and alpha set at .05 the study will have power of .90 or higher to detect an effect (R-squared) of .04 for any one test variable. Power is based on Model 2 error, which means that variables entered into the regression subsequent to the set of interest will serve to reduce the error term in the significance test, and therefore are included in the power analysis. We selected an effect size of .04 as the smallest effect that would be important to detect because smaller effects would not be of clinical or substantive significance. We also assume that this effect size is reasonable, in the sense that an effect of this magnitude could be anticipated in this field of research.

Results
Our research participants reported relatively few unmet needs. Twenty-percent reported no unmet need out of the 11 we queried, 28% reported no more than one, 46% reported no more than two, and 71% reported no more than three unmet needs. However, 15 caregivers reported four unmet needs, six reported five unmet needs, and two reported six unmet needs. Table 1 shows that that 57% of the variation in the number of unmet needs (standard error of the estimate = 1.1) was explained by whether or not the disability entailed multiple organ systems (effect=1.1, p<.001), whether or not an Anglo-American caregiver was a single parent (effect=3.4, p<.001), whether or not the caregiver was Latino (effect=4.6, p<.001), and variation in the income of Anglo American caregivers (effect=.12; p<.001). A post-hoc test for the main effects of income, post-secondary schooling, working or not, single parent status, Spanish-speaking only, and the interaction effects of ethnicity on post-secondary schooling, working or not, and severity of disability, yielded an $F_{8,67} = 1.682$, $P=.119$.

INSERT TABLE ONE ABOUT HERE

The correspondence analysis reported in Figure 1, which plots caregivers relative to their unmet needs and evaluations of services, reveals qualitative distinctions between the needs of Latino and Anglo American caregivers of disabled children. Latino mother/caregivers appear as red or orange symbols (orange indicates a Latino caregiver with an annual income greater than $23,000). Anglo-American mother/caregivers appear as blue, green (single-parents), and violet (annual incomes greater than $23,000). Latino mothers with the largest number of unmet needs reported needing a change in the educational program for their child and equipment, and experienced much frustration. Some Latino mothers, including most of the Latino mothers with high incomes, reported feeling supported, satisfied, and in control of their child’s therapy program. Most such mothers, those without high incomes, reported that they needed support, more information, equipment, and change in the existing therapy and/or educational program. The Anglo American caregivers who reported the largest number of unmet needs were single mothers and mothers with the largest annual incomes. Unlike Latino mothers, these Anglo mothers reported needs for a recreation program, day care, respite care, and a home health aide.

INSERT FIGURE ONE ABOUT HERE

Discussion

Not surprisingly, variation in the severity of disability predicts variation in the number of perceived unmet needs. It may be more difficult to meet the needs of children with more complicated health issues, and they may have more needs than children with less system involvement. Other sources of variation in both the number and kinds of unmet needs appear to reflect three key variables, two of which operate in relatively clear ways. Single mothers experience greater needs than other mothers because they lack a household division of labor to spread the workload. Mothers whose work generates a large income face a significant loss if they stop work to care for their child.

Advocacy effectiveness constitutes the third variable, and reflects historical cultural changes and a clash of contemporary cultures. First, over the last 20 years the culture of health care delivery for disabled children changed from centralized services provided by teams of specialists at specific locations (e.g., children’s hospitals) to decentralized services that required the coordination of many specialists (e.g., neurologists, orthopedic surgeons, and other medical specialists, medically-based therapy, and school based therapy). Centralized health care delivery required little parental advocacy
for their child. Decentralized services require a great deal of parental advocacy and active management of their child’s health care services.

Second, 20 years ago, patients generally assumed that medical providers not only knew what were the best and most appropriate forms of health care but also that providers would make them available. During the intervening years, fewer and fewer patients made that assumption. Instead, they took it upon themselves to advocate for their own health care and, if necessary, challenge the authority of medical providers. Contemporary caregivers of disabled children who assume that health care providers will provide expert opinions but will not facilitate obtaining services tend to make effective advocates for the services their child needs. Caregivers who assume, like earlier generations, that health care providers will provide expert opinions and will provide the services make ineffective advocates for their children.

Anglo American caregivers generally ascribe to the cultural assumption that health care providers will not make recommended services available. Consequently, their advocacy results in few unmet needs. When it does not, as with single mothers and mothers who earn high incomes, they report needs for childcare, home health aides, respite care, and structured recreational activities for the child. These needs remain unmet because programs for families of children with disabilities do not consistently provide such services.

Some Latino American caregivers also ascribe to the cultural assumption that health care providers will not make recommended services available. Consequently, their advocacy, like the advocacy of Anglo American caregivers, results in few unmet needs. Most Latino caregivers, however, assume, like earlier generations, that health care providers know best and will make available what is needed. These caregivers make ineffective advocates for the services their child needs. Because the cultural assumptions of these caregivers clash with the cultural assumptions of contemporary health care delivery, they report a significant number of unmet needs.

The kinds of unmet needs caregivers report reflects a universal set of childrearing priorities, although variation in social and physical environments creates variation in specific caregiver practices and expectations. Basic safety and health needs take first priority, independence in self-care activities take second priority, and age appropriate socialization and recreation take last priority. We expect caregivers to focus on quality of life issues only after they feel satisfied that basic health needs are met. Effective advocates report unmet needs (respite care, recreational programs) that reflect their success in seeing to it that their child has his or her basic health needs met.

Caregivers caught in the culture clash between patients and providers, however, report unmet needs (equipment, change in therapeutic programs) that reflect their lack of success in seeing to it that their child has his or her basic health needs met. Language barriers may contribute to the frustration reported by some Latino mothers, but a recurring theme among Latino American caregivers families was the assumption that health care providers would prescribe, obtain, and monitor treatment programs for the children. Although families often held strong ideas about the care they wanted for their children, they viewed health care providers as the experts who had the knowledge and power to obtain and monitor services. Latino mothers reported a non-confrontational approach to advocating for their children with providers, as compared to Anglo-American mothers.

As expected, families of children with more system involvement report more unmet needs than their counterparts who are less severely involved. Among effective advocates, single parents and working parents with high incomes report unmet needs because service delivery programs rarely provide the services they need. Ineffective advocates, by contrast, report unmet needs for basic health care. The need for caregiver advocates reflects an historical cultural change from centralized to decentralized health care delivery for children with disabilities. The former required no caregiver advocacy. The latter required caregiver advocacy and management of health care delivery. The difference between effective and ineffective advocates reflects different cultural assumptions about
the nature of health care providers and health care delivery. Culturally competent delivery of health care for disabled children requires us to identify cultural clashes in assumptions about the proper role of providers and, where appropriate, to help patients learn to advocate and manage their child’s health care delivery.

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References

FIGURE 1. Correspondence Analysis of Ethnicity and Unmet Needs

Symbol Size: proportional to number of needs

Red: Latino
Orange: Latino, high income
Blue: Anglo
Green: Anglo, single mother
Violet: Anglo, high income

*No Anglo Single-Mothers with High Incomes
Table 1.  
Regression Output for Number of Perceived Unmet Needs (n=80)

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Estimate</th>
<th>S.E.</th>
<th>t-ratio</th>
<th>p-value</th>
</tr>
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<tbody>
<tr>
<td>CONSTANT</td>
<td>-1.830</td>
<td>0.562</td>
<td>-3.258</td>
<td>0.002</td>
</tr>
<tr>
<td>Single Anglo Mothers</td>
<td>3.363</td>
<td>0.615</td>
<td>5.472</td>
<td>0.000</td>
</tr>
<tr>
<td>Income (Anglo Mothers only)</td>
<td>0.122</td>
<td>0.028</td>
<td>4.371</td>
<td>0.000</td>
</tr>
<tr>
<td>Latino Mother</td>
<td>4.557</td>
<td>0.663</td>
<td>6.876</td>
<td>0.000</td>
</tr>
<tr>
<td>Severity of Disability</td>
<td>1.100</td>
<td>0.255</td>
<td>4.318</td>
<td>0.000</td>
</tr>
</tbody>
</table>

Adjusted squared multiple R: 0.570  Standard error of estimate: 1.090

For main effects of income, post-high school training, working or not, single parent, Spanish-speaking only, and interaction effects of ethnicity*post high school training, working or not, and severity of disability, $F_{8,67} = 1.682$, $P=0.119$