Title: Caregiving Experiences of Latino Families with Children with Autism Spectrum Disorder
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Objective: Understand the caregiving experiences of Latino families with children with ASD, including daily activities, coping strategies, and service utilization

Related Information:
- In general, parents of children with ASD report caregiving challenges and increased stress levels, depression, anxiety, and physical health challenges
  - The Latino population is the largest ethnic group in the U.S. – few studies specifically focus on Latino families
- There is a risk of stereotyping culture; however, it is important to consider the role of culture in working with families
  - Different ways researchers have described Latino cultures:
    - People can do little to alter their fate and therefore do not actively seek early services
    - Strong identification with the immediate and extended family, valuing the needs of the collective over those of the individual, avoid conflict and promote pleasant relations, have defined gender roles, and have a present time orientation
    - 61% of Latinos tend to use a protective child-rearing style – favor warmth and demandingness. Focus little on autonomy granting
  - Reduced access to health care for Latino families is of concern
    - Latino families tend to have ASF diagnosed later and less often than in non-Latino families
      - Restricted access to services and education – low economic resources, lack of awareness of services, a feeling of disempowerment, low levels of parental acculturation, and decreased English proficiency
      - Clinicians’ difficulty in identifying signs of ASD in Spanish-speaking families
        - Some diagnostic tools may not provide the same information when used with Latinos, even when they have been translated into Spanish

Methods: Descriptive qualitative research methodologies. Study included 15 Latino parents (12 mothers and 3 fathers) from 13 families who state Spanish or English as their primary language. The families each has children between the ages of 2 and 8 years old who have been diagnosed with ASD by physicians or psychologists.

- Children
  - Diagnosis between the ages of 18mo and 6 years old
  - Age at time of interviews – 3 to 8 years old

- Interviews with parents:
  - In depth, semistructured
  - 4 interviewers were fully bilingual and bicultural
  - Interviews conducted in the language of the parents’ preference
    - 5 families chose English, 6 in Spanish, 5 in English and Spanish
  - Parents’ chose location of interviews – home or clinic where children received therapy services
Results: It was found that Latino families of children with ASD experience similar issues as non-Latino families, with unique matters that impact service utilization. Four themes were identified during the study. They are listed below. All of the themes were influenced by family and community.

1. Dealing with diagnosis
   a. Mothers felt the need to deal with the unknown
   b. Parents reported that they sought information through the Internet, local organization, and family members and neighbors
   c. Extended family members provided information and served as support; however, acceptance of an ASD diagnosis was a slow process
   d. Copying mechanisms:
      i. “Americans label everything”
      ii. “the kid is badly behaved”
      iii. “the child is smart so he can’t have autism”
      iv. the “wait and see” attitude
      v. belief in power of religion

2. Dealing with stigma and isolation from family and community
   a. Feelings of discomfort and anger with having a child singled out in the community and resorted to copying strategies to avoid “chisme” (hearsay)
      i. Keeping diagnosis a secret
      ii. “Cover up” child’s atypical behavior
      iii. Social isolation
      1. Stay in the house to prevent others from criticizing

3. Understanding the role of mothers in changing family routines
   a. In many Latino cultures, gender roles are strongly established
      i. Mother’s role is to care for children – carry responsibility of changing family routines in response to ASD
      1. Mothers tend to get support from other women in the family
      ii. Fathers are typically not involved with planning
      1. Mothers deal with planning of outings for children with ASD along with anticipating husband’s level of comfort

4. Utilizing services
   a. Main factors revolve around lack of knowledge and language barriers
      i. Lack of understanding about ASD diagnosis and language barriers can prevent child from fully accessing services
      1. Parents may receive more information from a Spanish-speaking classroom assistant rather than service providers
      2. Lack of information and follow-up provided in Spanish
   b. Gaining advocacy skills and knowledge with navigating the system has reported to make parents proud

Conclusion: Services need to be provided in culturally sensitive context that address both the child and the families’ unique needs

- Study supports previously identified factors that impact utilization of services: lack of information in Spanish that can increase awareness of health care and educational resources and a lack of professionals trained to understand family values and cultural beliefs, including, but not limited to language barriers.
- Health literacy is CRITICAL – degree to which people have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions
**Limitations:** Small sample size, limited geographic location, and concept that being Latino is not a uniform experience (multiple cultural factors)

**WHAT DOES THIS MEAN FOR US??**
1. Be conscious of providing culturally sensitive services that meet the unique needs of our students and families
2. Potentially provide educational opportunities to the extended family because they may form a key component in the family structure
3. Become more familiar with concepts of health literacy and how it affects the services being delivered
4. To your best ability, ensure parents fully understand the information provided, including ongoing interactions. When possible, do not only rely on written material. Utilize verbal explanation and ongoing consultation with assistance from interpreter, when appropriate.

**QUESTIONS TO CONSIDER:**
1. With the majority of APS’ student population being Latino (staff population mainly non-Latino), what is the district currently doing to support health literacy and cultural sensitive? Per building? Personally? What can we do, big or small, to start supporting our families more?