

PS 20**CLD Families' Views on Autism: An Ethnographic Perspective**

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Data from large national surveys indicates that in the U.S. today, there are approximately 425,000 children with ASD; 114,000 of these are younger than 5 years old (Fombonne, 2003). More recent data suggest that today, 1 in 150 children are born with ASD (Autism Society of America, 2007).

A possible cultural challenge for SLPs who deal with CLD children with ASD and their families is that in many of these families, early childhood independence is not seen as important (Roseberry-McKibbin, 2007). In addition, CLD families may have other beliefs and values that the SLP is not aware of. Lack of awareness of these beliefs and values could negatively impact service delivery to CLD children with ASD (Callicott, 2003; Dyches, Wilder, Sudweeks, Obianker, & Algozzine, 2004).

Prelock, Beatson, Bitner, and Ducker (2003) discuss working with these families. They encourage SLPs to operate within a "strengths" perspective instead of a "cultural destructiveness" perspective. In the latter perspective, SLPs view cultural differences as a "pathology." In the "strengths" perspective, the family's pain is acknowledged and the team works to facilitate a mutually trusting relationship. A large part of this is believing that the family's strengths will be useful in providing solutions. Before this can happen, however, SLPs need to understand how CLD families view ASD and what they believe about intervention.

METHODS AND RESULTS

Accordingly, in this study, the first author interviewed families from African (Ghana & Eritrea), Iranian, Mexican, Korean, Filipino, Indian, and Japanese backgrounds. In each family, there was a child with ASD. The first author had worked closely with the ASD children in these families, and had gotten to know the children and parents fairly well. The following questions were asked of the parents:

1. What do you think causes autism?
2. What do you believe should be done to treat it?
3. What has it been like for you to have a child with autism?

The families in this study believed that ASD could be caused by a number of variables. These variables included:

- a. viruses
- b. heavy metal toxicity
- c. exposure to environmental teratogens
- d. compromised immune system of the child
- e. immunizations****
- f. allergies
- g. genetics
- h. parental age
- i. changes in climate conditions

In terms of what should be done to treat ASD in children, families listed the following:

- a. dietary changes
- b. re-examining the immunization schedule
- c. research to determine causes and potential cures
- d. intensive behavior modification programs
- e. educating society (e.g., teachers, physicians) about how to deal with children with ASD
- f. early intervention including speech therapy, occupational therapy, and high-quality in-home programs
- g. support for parents (e.g., support groups, websites, books, videos)

In answer to the question "Describe your experience parenting a child with autism. What has it been like for you?" the parents stated the following:

"Amazing! It has opened up a whole new world to me. At times it is painful and I worry about his future. We are not alone and need to work on all possibilities for these kids' futures."

"At the beginning it was very difficult. Now we try to come up with solution and we are accepting it, even though we know there is no cure for it."

“Very challenging and frustrating. It was very hard, especially in the initial diagnosis stage. [But] with several therapy interventions, there has been a lot of improvement with my son.”

“It has been a learning experience. We feel that we are blessed that our child isn’t more severe. [It has been very hard] trying to keep up with the demanding schedule of therapies...Also, since we are also treating him with biomedical interventions, it makes things more difficult because he is on a restrictive diet and has to take a number of supplements and medications which we pay for out of pocket. No insurance will cover these therapies. It is very costly. We also need to know the law in order to best advocate for our child.”

“[It has required] patience, patience, patience....This has taught us to be compassionate; we no longer take things for granted, we appreciate all the small and tiny achievements of our child. And we just take it one day at a time.”

“Exhausting, eye-opening, and grateful for everything that our son is. He is healthy, happy, and has brought so much to our family. I wouldn’t change one thing about him!”

CONCLUSIONS

In this small ethnographic study of culturally and linguistically diverse families with an ASD child, it was found that the families tended to hold mainstream beliefs about the causes of ASD. They believed that intervention was important, and were honest about the difficulties they were experiencing in parenting ASD children. All families viewed their children positively despite the ASD diagnosis, and accepted their children for who they were.

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