Bridging the Gap: Raising Awareness & Increasing Accessibility to Autism Services in Non-English Speaking Communities



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Purpose

- Children make greater gains when they enter a program at a younger age
- Imperative that we make a concentrated effort to meet the needs of an under-identified population of children
- In order to accomplish the goal of accurately identifying children with autism, it is important to train those in the communities to recognize the indicators of autism and that we understand the cultural issues of our non-English speaking families

Research

- University of Pennsylvania's Health System School of Medicine:
 - Minority children are diagnosed 2-5 years later than their white counterparts
- Center for Disease Control (CDC):
 - Average age for diagnosis of Caucasian children is two years
- Schwartz & Davis (University of Washington):
 - Delays in identification often lead to delays in the provision of adequate services
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 All children with autism spectrum disorders benefit from early intervention
 - Even though autism is a lifelong disability, some children make remarkable progress as a result of early intervention.

Southwest Kansas Community

- In the southwest region of Kansas there are a common set of barriers to quality services for children with autism spectrum disorders, including:
 - Pediatricians
 - Diagnosticians to provide a multi-disciplinary approach to diagnostics
 - Services
- Family practice physicians and/or physician assistants provide medical services
- The American Academy of Family Physicians have not adopted the American Academy of Pediatricians recommendations with regards to autism spectrum disorders; as a result they have not incorporated into their practice the same rigorous standards for developmental surveillance that are recommended and practiced by pediatricians
- Educational autism teams
 - Trained on the gold-standard assessment tools used to diagnose autism
 - Serve as collectors of the information and doctors at KU's Center for Child Health and Development via telemedicine give the diagnosis

Challenges of Diagnosing in a Bilingual Community

- Non-English speaking children and their families may not be referred for developmental evaluations that would identify Autism Spectrum Disorders. Physicians and service providers often have difficulty gathering developmental history and communicating effectively with non-English speaking families.
- Frequently, families are unaware of the "red flags" of autism.
 Autism is a spectrum disorder, which means that not all children will have the same symptoms or the same severity. Even if a family knows of another child with an autism spectrum disorder, that child's behavior may look different than their own child's, making identification more difficult.
- Teachers and physicians sometimes attribute delayed communication, difficulty in social interaction and behavioral issues to bilingual environments and cultural differences rather than considering a developmental disorder.
- Culture and familial attitudes toward disability may impact the family's feeling of acceptance while seeking help for their child.
- Behaviors associated with autism may not be considered problematic in some cultures or families.
- Finally, mistrust of authority and difficulty navigating an unfamiliar education and health system can play key roles in delaying access to services.

Where did we Start?

- First we had conversations with parents of diagnosed children to learn about the challenges they faced in seeking diagnosis
- We sought collaboration with a trusted community agency
- We provided training for interpreters on ethics, etiquette, and empowerment
- Distributed Learn the Signs Act Early materials
- Community Awareness:
 - Local media: Newspaper/Radio
 - Parent Fair
 - Child Find Screening

