

An Autism Clinic Pilot is Born:
**The Experiences of
African American and
Latino Families of
Children with Autism**

By:

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Over 150 culturally / linguistically diverse parents called CFI looking for help with:

- Special Education
- Medicaid Waivers
- Information and Referral



Focus Groups

The aim of the focus groups was to explore health care quality and perceived health care disparities by Hispanic and African American families who have children with disabilities or special health care needs.

Report can be found under the Resources tab at:

www.centerforfamilyinvolvement.vcu.edu



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Care Coordination

- Most parents indicated that their primary doctor was very helpful in providing referrals to appropriate providers
- Areas of Concern:
 - Health care providers are often not referring children for **behavioral health** concerns.
 - Health care providers are not telling parents about **Early Intervention**.
 - Health providers make an unintentional error in diagnosing the disability or special health care need.



Care Coordination

- Parents are not aware of parent resources in the community
- Health care providers are often not providing parents with the information they need about their child's disability or special health care needs
- When they are given resources, they are not accessible because of language barriers
- Parents expressed feelings of being overwhelmed by having to do the care coordination themselves





Family-Centered Care

What is family?

Family-Centered Care



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Family-Centered Care



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Language

- This is the most significant barrier to accessing the healthcare and special education system in Virginia
- Unintentional delay on the part of providers when referring to specialists
- Inappropriate language services



Language Barriers are not only foreign language issues:

- Lack of effective communication
- Cultural barriers and nuances (verbal and non-verbal communication)
- Special education, health literacy and comprehension



Language

- Language delays are mistaken for perceived consequences of bilingualism
- Local school systems usually “treat” learning difficulties in bilingual children by assigning them ESL status, and providing them ESL support only.
- Many bilingual children’s developmental disabilities go unnoticed for long periods of time.



What is Cultural Brokering?

- The act of bridging, linking, or mediating between groups or persons of differing cultural backgrounds for the purpose of reducing conflict or producing change (Jezewski, 1990)
- A cultural broker acts as a go-between, one who advocates on behalf of another individual or group (Jezewski & Sotnik, 2001)



Latino Autism Clinic Pilot

Data Summary for Latino Clinics	
Number of Children Seen	6
Male	2
Female	4
Number of Children Diagnosed with Autism	4

Date	Age	Sex	Location	Diagnosis
09/12/2011	6.10	Female	Richmond,VA	Anxiety Disorder; Mixed Receptive-Expressive Language Disorder
10/10/2011	6.2	Female	Richmond,VA	Pervasive Developmental Disorder – Not Otherwise Specified
11/14/2011	6.5	Male	Newport News,VA	Expressive Receptive Language Disorder; Learning Disability Rule Out
01/09/2012	3.10	Female	Goddrich,VA	Autistic Disorder
02/13/2012	5.1	Female	Newport News,VA	Autistic Disorder
03/12/2012	4.3	Male	Richmond,VA	Autistic Disorder



Latino Autism Clinic Pilot

- Called parent to perform intake in Spanish
- Met with parent to fill out forms together – 2-3 hour process
- Met parent at the Interdisciplinary Clinic Evaluation - Interpreter plus Cultural Broker
- 6 weeks later, parent receives report translated into Spanish
- Cultural Broker remains in touch with the parent to help bridge into intervention.



African American Clinic Pilot

Data Summary for Pilot African-American Clinic 2011-2012	
Number of Children Seen	6
Male	4
Female	2
Number of Children Diagnosed with Autism	2

Date	Age	Sex	Location	Diagnosis
10/12/2011	7.9	Male	Lynchburg, VA	Developmental Learning Disorder, Not Otherwise Specified
10/19/2011	7.0	Male	Lynchburg, VA	Attention Deficit Hyperactivity Disorder
12/7/2011	6.5	Female	Fredericksburg, VA	Autistic Disorder
12/21/2011	6.9	Female	Richmond, VA	Rule out Learning Disorder
1/18/2012	7.6	Male	Highland Springs, VA	Asperger's Syndrome
1/25/2012	6.7	Male	Richmond, VA	Communication Disorder with features of Pervasive Developmental Disorder- Not Otherwise Specified

African American Clinic Pilot

- Referrals came from providers or parents
- Intake done by coordinator at CAS, offered the services of Cultural broker (CAS clinic coordinator gives the referral to the cultural broker)
- The Cultural Broker:
 - contacted the family via telephone to explain the process, build rapport with the family, talk with parent about their concerns
 - met with family 15-30 minutes prior to start of clinic
 - waited with parents while child being evaluated
 - assisted family as needed, joined family in team meeting, helped parent(s) recall necessary information, answer questions, ensure communication between clinic team and parents were parent-friendly
 - provided follow up support



Latino Community

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