Connections between Family Centered Care and Medical Homes of Children with Neurodevelopmental Disabilities: Experiences of Diverse Families.

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STUDY PURPOSE

- To investigate whether family race/ethnicity, in addition to parent and child characteristics,
- significantly influenced family perceptions of family centered care (FCC) delivered in primary health care,
- to children with developmental disabilities and their families in three areas of medical home services:
  1. Family-provider partnership
  2. Care practices and policies, and
  3. Community coordination and follow-up.

THEORETICAL SUPPORT

- Based on the life course theory for optimizing children's developmental trajectories (Halfon et al., 2014), and
- the ecological systems theory for promoting healthy family functioning in different environments (Bronfenbrenner, 1986),
- understanding the connections among the family perception of FCC in health care, family satisfaction with medical homes, and
- cultural sensitivity,
- may help to improve children's health outcomes (Abraido-Lanza, Cespedes, Daya, Florez, & White, 2011; King et al., 2015).

STUDY METHOD

- **Secondary Data Analysis:** Cross-sectional design, original community survey conducted in from 2010 – 2012 in Washington, DC.
- **Study Inclusion Criteria:** District residence, English speaking parent, child with a developmental disability, whose condition was diagnosed by a physician, and whose age was between 1-12 years.
- **Measures:**
  - **Demographics:** mothers' chronological age, education in years completed, family yearly income, and self-identified race/ethnicity.
  - **Parental Satisfaction with Child Medical Home:** (a) presented with a definition of medical home, based on the National Center for Medical Home Implementation (NCMHI), 2014, (b) then were asked whether satisfied with it on a Likert scale of 1-5.
  - **Parents' Perception of FCC:** Family-Centered Care Self-Assessment Tool **(FCC-SAT),** available from Family Voices (2008) (familyvoices.org).
- **Analyses:** Unadjusted race comparisons, MRA and Hierarchical LR.
- **Ethics:** IRB approved.

STUDY SAMPLE: N =122

Table1 Comparison of Study Participants' by Race

Variables	Race/Ethnicity Group: Black[1] n=42 (34%)	White[2] n=39 (32%)	Other[3] n=41 (34%)	Chi-Square (df), p, Effect size
Satisfaction with Medical Home				χ^2 (2) = 11.18, p = 0.004
YES	14%	49%	32%	Cramer V = 0.30
NO	86%	51%	68%	
Mother's Age				χ^2 (4) = 29.61,
21-30 years	49%	0%	25%	p < 0.001
31-40 years	38%	40%	39%	Cramer V = 0.457
41-45 years	13%	60%	36%	
Education				χ^2 (4) = 34.73,
High School	69%	10%	32%	p < 0.001
4 Year College	31%	72%	46%	Cramer V = 0.471
Post-College	0%	18%	22%	
Income†				χ^2 (2) = 30.613,
$0 – $79,000	88%	28%	49%	p < 0.001
$80,000-100,000	12%	72%	51%	Cramer V = 0.501
Child's Age				χ^2 (2) = 26.25, p < 0.001
1 – 5 years	71%	21%	34%	Cramer V = 0.421
6 – 12 years	29%	79%	66%	
Child Condition				χ^2 (10) = 7.91,
Autism	33%	36%	34%	p>0.05
ADHD	21%	20%	22%	NS
Cerebral Palsy	24%	10%	15%	
Down Syndrome	7%	18%	7%	
Fragile X	5%	10%	15%	
	10%	5%	7%	
Sibling CSHCN[a]				χ^2 (2) = 10.83,
YES	31%	49%	15%	p = 0.004
NO	69%	51%	85%	Cramer V = 0.286
No. Specialists				χ^2 (6) = 7.82,
0-1	20%	31%	30%	p >0.05
2-3	59%	49%	50%	NS
4+	21%	20%	20%	

Notes: † Median Income = $ 80,000 for District of Columbia, [a] CSHCN = Child with Special Health Care Needs, [1] Black = African American Non-Hispanic, [2] White = Caucasian Non-Hispanic, [3] Other Non-White = Asian, Hispanic, Other.

STUDY RESULTS

Table 2 Multiple Regression Analyses (N=122)

Dependent Variable →	Family Centered Care in Family and Provider Partnership	Family Centered Care in Care Practices and Policies	Family Centered Care in Community Coordination and Follow-up
Predictors ↓	b (SE) βeta	b (SE) βeta	b (SE) βeta
Mother Age	NS	NS	NS
Mother Ed.	NS	1.21 (0.6) 0.204*	NS
Family Income	-1.77 (0.8) 0.240**	-4.51 (1.2) -0.425***	-0.80 (0.4) -0.257**
Child Race (White=0)	NS	-5.59 (2.9) -0.277*	-2.90 (0.9) -0.315**
Child Age	0.56 (0.3) 0.191*	1.61 (0.4) 0.385**	0.30 (0.1) 0.240*
No. of Siblings	NS	NS	NS
Sibling CSHCN	-0.54 (0.7) -0.124**	-1.56 (2.6) -0.149*	-0.98 (0.8) -0.105*
No. Specialists	-1.22 (0.7) 0.137*	-2.15 (1.1) -0.155*	NS
Satisfaction	13.96 (1.7) 0.636***	10.91 (2.6) 0.345	4.91 (0.8) 0.532***
R^2 (Adj. R^2)	0.506 (0.499)	0.459 (0.450)	0.403 (0.395)
F (9,116)	12.11***	10.01***	7.94***

Table 3 Hierarchical Logistic Regression - Predicting Satisfaction with Medical Home

Variables Entered	4 Step Model b (SE)	OR	Sig.
Child - Down S.			NS
Child - ADHD			NS
Child - Cerebral Palsy			NS
Child - Autism			NS
Child - Other DD			NS
Race Non-White =1	-2.68 (1.2)	0.07	0.025
Child Age			NS
No. Sibs			NS
Sib CSHCN	-2.61 (0.1)	0.07	0.017
No. Specialists			NS
Mother Age			NS
Mother Education			NS
Family Income			NS
FCC-Parent Provider	0.39 (0.1)	1.45	0.001
FCC-Care Practices	0.42 (0.1)	1.62	0.005
FCC-Community	0.34 (0.1)	1.40	0.007
Constant (Intercept)	-9.12 (1.95)		
Omnibus Test	χ^2(df11) = 96.23, p<0.001		
Hosmer-Lemeshow	χ^2(df8) = 7.43, p>0.05		
Nagelkerke R-Square	0.778		
Overall Classification Correct	92%		

STUDY LIMITATIONS

- Unique non-generalizable sample
- Maternal reports
- Family Income > National Average Income
- Race sample constrained by White and Non-White analyses

STUDY POLICY IMPLICATIONS

IMPROVE CULTURAL SENSITIVITY IN DELIVERY OF MEDICAL HOME SERVICES.

1. Professionals' need to adopt a learner's perspective.
2. Examine health care provider biases.
3. Identify family preferred methods of communication (oral & written).
4. Identify family barriers for communication and engagement of health care services.
5. Each year examine and regularly review family comprehension of child developmental needs.
6. Each year review the child's diagnosis and assure family comprehension of the child' diagnosis.
7. Engage in intentional trust building with family.
8. Identify family spiritual or religious practices for support.
9. Maintain a current list of ancillary and community support services.
10. Develop a coordinated plan for monitoring the child's developmental progress in the community in which the child lives.