Health Care Disparities
Focus Groups:
The Experiences of Latino and African American Parents of Children with Disabilities and Special Health Care Needs
The following report was developed by the Partnership for People with Disabilities at Virginia Commonwealth University for Virginia Department of Health through a Health Resources and Services Administration (HRSA) grant.
Eight focus groups were conducted of African American and Latino parents who have children with a disability or special health care need to determine the extent to which access to care coordination and family-centered care are impacted by race or ethnicity. Results from the 54 parents illustrate that care coordination from health providers is largely absent, but is not perceived to be a result of racial discrimination or bias. On the other hand, parents recognized that elements of family-centered care, particularly the level in which they feel heard by health care providers, may be affected by their race or ethnicity. Most of the parents reported that health care providers spend insufficient time with them and that health care providers often disregard their concerns. Feeling heard by health care providers does not translate into preferring a doctor of the same race/ethnicity or establishing trust in relationship to health care providers.
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Health Care Disparities Focus Groups:  
The Experiences of Latino and African American Parents of Children 
With Special Health Care Needs 

The National Survey of Children with Special Health Care Needs, as well as state findings, have identified a much lower level of satisfaction with their health care and greater health disparities among racial minorities than Caucasian families. African American and Hispanic families of children with special health care needs/disabilities tend to access health care less frequently than white families, and minority families tend to report less care coordination and family-centered care. To explore health care disparities, the Virginia Department of Health contracted with the Partnership for People with Disabilities at Virginia Commonwealth University to conduct focus groups of African American and Hispanic families who have children with special health care needs. The research is an important step in providing equitable health care to all families and in educating families of children with disabilities on health care access, care coordination, and family-centered care. The major goals of the project are to explore the barriers minority families perceive in obtaining health care coordination and family-centered care.

PURPOSE

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. Specifically, the focus groups addressed the extent to which families report receiving coordinated health care and family-centered care and how race/ethnic factors affect coordination of health care and family-centered care. The overall purpose of the focus groups was to identify areas in which both healthcare providers and families can be educated.

1 Board on Health Policy. (2003). *Unequal treatment: Confronting racial and ethnic disparities in health care.*
to bridge health care disparities and create coordinated, family-centered care for children with disabilities and special health care needs.

**METHODOLOGY**

There were a total of eight focus groups held—four focus groups of African American families and four focus groups of Hispanic families. All of the focus groups for Hispanic families were conducted in Spanish.

Focus groups were scheduled at conveniently-located sites—a church in Alexandria and Portsmouth, a public library in Richmond and in Alexandria, a hotel meeting room in Portsmouth, and at the Key Center, a public school for students with special health care needs/disabilities aged 5 to 22 in Springfield, Virginia. The sites were selected based on convenience, availability during the scheduled dates, and cost. Each site has a private room to allow the focus group participants to discuss their opinions and experiences without concern of being overheard. The only persons in the room were the facilitator, notetaker, and focus group participants.

Family members were recruited through community representatives, schools, and parent organizations. Potential subjects contacted the Partnership for People with Disabilities on a dedicated telephone line and left a message with their contact information. The Spanish-speaking focus group facilitator contacted the Spanish-speaking callers. The project staff who responded to the callers determined whether the potential subject was eligible by asking qualifying questions. The criteria for inclusion in the focus group include:

- The child has a learning, mental health, behavioral, physical, or sensory disability in which:
  - Onset occurred at least 12 months ago and is expected to be ongoing.
  - Child needs and receives current ongoing health care services, treatment, counseling or medication.
- Child receives service, treatment, or counseling at least semi-annually.
- The family member and child are of African American or Latino descent.
- The child with a disability is between one and 21 years old.
- The child lives with potential subject at least half the time.
- The potential subject may have a biological, adoptive, or informal (e.g., mentorship or faith) relationship to the child, but must have had caregiving responsibilities for most of the child’s life.

The screener explained to eligible subjects the scope of the study, its purpose, their rights, the research incentive, and the format of the focus groups. Specifically, potential subjects were informed of the following focus group practices.
Format

- The focus groups for Hispanic families will be conducted in Spanish.
- Each focus group will last sixty to ninety minutes.
- Participants will receive a $100 stipend, to be mailed after the focus group.
- One facilitator, one notetaker, and 4 – 10 other participants will be present at each focus group.

Requirements

- Subjects need to arrive 15 minutes early to complete the information sheet and Informed Consent form (see appendix).
- Participants must provide their signature and social security number on the payment receipt form to receive payment.
- Subjects need to provide their own transportation.
- Participants may not discuss outside the focus group the content of the discussion or who was in attendance. The need to keep the identity and discussion content private will be emphasized strongly.

Informed Consent

- Subjects will need to sign the Informed Consent and payment receipt forms. The consent form documents that the participant gives permission for tape-recording of the session and assures confidentiality.
- Participants will be assured of confidentiality of their data.
- The focus groups will be tape-recorded by two tape recorders (one tape recorder serves as a back-up in case of malfunctioning).
- Non-identifying information will be shared and presented to external groups. Identifying information will be kept confidential.
- The facilitator will ask questions about the participants’ experiences and opinions. They are free to not answer any question, but participation is strongly encouraged.

Subjects who were interested and eligible were then scheduled for participation in the focus group. The Co-PI and Spanish group facilitator sent emails and made phone calls to remind participants and reiterate the location, directions, and policies.

Each participant completed an information form prior to the focus group that requested demographic information. The form contained no identifying information, but provided a context to the responses during analyses. Information collected includes age, gender, marital status, education, length of time in the state, number of children and ages, military status, and general income level.
Each focus group was facilitated by an experienced group leader. The focus group facilitators and notetakers were trained and piloted a focus group for practice. Both the facilitator and notetaker for the African American focus groups are African American and have a child with a disability. Both the facilitator and notetaker for the Latino focus groups are Latino, bilingual, native speakers, and have a child with a disability.

At the focus group, the facilitator started by explaining the purpose of the focus group and clarified the protection of human research subjects—their rights, risks, benefits, privacy, and confidentiality. The facilitator ensured that each participant signed the Informed Consent and payment receipt forms, responded to questions from the participants, and explained the purpose of the focus group. The notetaker recorded significant verbal and non-verbal exchanges, set up and monitored the tape recorders, and attended to logistics. The facilitator presented each question, one at a time, and facilitated discussion, assuring equitable participation, calling on those who talked little and re-directing those who talked excessively. After the focus group, the facilitator and notetaker discussed the focus group and recorded the themes, surprises, and impressions on a debriefing form.

RECRUITMENT

The study utilizes purposive and snowball recruitment methods. There was a three-step approach in recruiting African-American and Hispanic family members of children with disabilities. The recruitment materials were printed in both English and Spanish. The recruitment materials and processes were approved by the Institutional Review Board at Virginia Commonwealth University.

The African American and Hispanic cultural brokers, who are staff at the Partnership for People with Disabilities and served as focus group facilitators, identified several community representatives who were helpful in contacting potential subjects. Additionally, the Co-PI also telephoned and emailed parent organizations in Virginia, requesting they post recruitment announcements on their listserv and in their newsletters, and sent recruitment flyers. Parent organizations are support groups of family members of children who have disabilities, which included Parent-to-Parent, Dreamcatchers, the ARC, Project River, Special Education Advisory Committees, and Guide By Your Side.

The PI arranged for school nurse coordinators to be informed of the study, requesting that they distribute recruitment flyers to parents of students with special health care needs or disabilities. Several school nurses contacted the Partnership to obtain additional information about the focus groups to share with parents.
HUMAN RESEARCH SUBJECT PROTECTION

Each participant was asked to provide consent and sign the Informed Consent form. (See appendix for Informed Consent form.) The Informed Consent form was verbally explained and discussed with the participant during the screening and again at the time of the focus group. The Informed Consent form, approved by the Institutional Review Board at Virginia Commonwealth University, states that all information will be kept confidential, that the discussion will be tape-recorded, and that participants have a right to withdraw from the study or refuse to answer any question. The screening phone call, pre-focus group discussion, and focus group discussion were conducted in English for the African-American focus group and in Spanish for the Hispanic focus group participants, and Informed Consent materials were provided in English and Spanish.

DATA ANALYSIS

The major processes utilized during the data analyses involved data checking, validation, and analysis. During data checking, the digital recording of each focus group was transcribed and then checked for accuracy by reviewing the transcript along with the digital recording. The digital recordings of the focus groups conducted in Spanish were translated, transcribed, and checked for accuracy by a team of five Spanish-English bilingual translators.

Validation of data was a critical aspect of the data analysis process. The research team employed three different strategies to validate data—member checking, debriefing, and final review. Member-checking was conducted during the focus groups, in which the facilitators checked with the focus group participants that the communication being heard accurately represented the communication being delivered verbally and non-verbally. The focus group facilitators listened to the participants’ responses to a specific question, then summarized for the focus group what they heard. The facilitators asked the focus group if their summary was accurate, which allowed the focus group participants to validate the summary, clarify their responses, or provide additional information.

The facilitator and notetaker met immediately after each focus group for a debriefing session to discuss overall impressions, themes, and findings. The themes and findings were recorded on debriefing forms. In addition, the notetaker wrote observations throughout the focus group, noting non-verbal communication, emotional responses, and group dynamics that could provide greater insight and context to the focus group digital recordings. A final review was conducted when all focus groups were completed, during which the focus group notetakers and facilitators were assembled to provide feedback about the research findings. During this final review, the major themes and conclusions were explored and the notetakers and facilitators validated the findings and provided context, recommendations, and insight.
The data analysis involved coding the transcripts, a total of 55,608 words. The text was separated into about 2,000 major narratives that express a single response; this could be a few words or several sentences. The narratives were coded along the general research topics explored, then sub-coded for emerging themes. For all of the research topics, there were outliers, participants who had experiences and opinions that differed from the majority. These narratives were analyzed both independently and in conjunction with the emerging themes.

RESULTS

A total of eight focus groups were conducted—four groups of African American families and four groups of Latino families, which were facilitated in Spanish. The focus groups were held in the three most densely populated areas in Virginia--Richmond, Tidewater, and Northern Virginia. Specifically, focus groups were held for separate African American and Latino parent groups in Richmond, Portsmouth, Alexandria, and at the Key Center in Springfield, with each area holding both an African American and Latino focus group. The Key Center is a Fairfax County Public School for children with moderate to severe disabilities. Students range in age from 5 to 22. The Key Center provided the use of two rooms at the school and helped recruit parents to participate in the focus groups.

PARTICIPANTS

A total of 76 individuals contacted the Partnership for People with Disabilities with interest in participating in the focus groups. Of these, 68 individuals were eligible based on screening criteria and the others were ineligible, typically due to the parent being a race other than African American or Latino. Of the 68 individuals screened and invited to participate, 54 were able to participate in the focus groups, a total of 27 in the African American focus groups and 27 in the Latino focus groups.

Nearly all (n=50) of the 54 participants are parents of children with special health care needs. Two participants are grandmothers; one is an adult sibling; and one is an uncle who adopted his nephew when his sister died. All participants live full-time with the child with special health care needs and have caregiving responsibilities. As shown in the following table, most participants (89%) are women and their ages are typically 30 – 49 years old.
Table 1. Demographics of Focus Group Participants

<table>
<thead>
<tr>
<th>Race</th>
<th>Age</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>African American</td>
<td>27</td>
<td>50%</td>
</tr>
<tr>
<td>Latino</td>
<td>27</td>
<td>50%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>54</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table 2 provides more information about the focus group participants. Most are married (62%) and have lived in Virginia less than half of their lives, but longer than two years (56%). Most are well-educated, with 26 percent having a college degree and 13 percent having a graduate degree.

Table 2. Other Demographics of Focus Group Participants

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Education</th>
<th>Years In Virginia</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Married</td>
<td>32</td>
<td>62%</td>
</tr>
<tr>
<td>Single</td>
<td>11</td>
<td>21%</td>
</tr>
<tr>
<td>Divorced/</td>
<td>8</td>
<td>15%</td>
</tr>
<tr>
<td>Separated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td>Total</td>
<td>52</td>
<td>100%</td>
</tr>
</tbody>
</table>

8 Total frequencies differ because some participants did not provide information.
Families of focus group participants tend to be middle class (55%) and have private health insurance (34%), Medicaid (33%), or a combination (15%). About the same percentage of families have one child (26%) as those who have two (28%), three (25%), or more children (20%). Income levels were self-reported and based on the judgment of the participant.

Table 3. Characteristics of the Families of Focus Group Participants

<table>
<thead>
<tr>
<th>Location</th>
<th>Income level</th>
<th>Number of Children</th>
<th>Health Insurance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Richmond</td>
<td>12</td>
<td>1</td>
<td>14</td>
</tr>
<tr>
<td>Northern Va.</td>
<td>12</td>
<td>2</td>
<td>15</td>
</tr>
<tr>
<td>Tidewater</td>
<td>10</td>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>Key Center</td>
<td>20</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>54</td>
<td>49</td>
<td>53</td>
</tr>
</tbody>
</table>

DISABILITY/SPECIAL HEALTH CARE NEEDS OF THE CHILDREN

To qualify for the focus group, the family member must have a child with a health concern, which could be any type of mental health, behavioral, physical, or sensory disability or special health care need. The children of the focus group participants have a variety of special health care needs. As shown on Table 4, the most common disability/health care need is autism. Most of the family members report a co-occurring disorder, such as a speech disorder and cerebral palsy or autism.

In all, there were a total of 60 children (37 boys and 23 girls) discussed by the participants in the focus group. One parent has three children with special needs and two parents have two children with special needs. The other parents have one child with a disability or special health care need. Children range in age from 3 to 20 years old.

Many of the participants indicated that their child most often sees a neurologist, psychiatrist or other specialist more than they see a primary care doctor. The specialist often assumes responsibility for most of the care of the child with a special health care need, though a primary care doctor is still typically seen for physicals or routine childhood illnesses. In most cases, the children are being treated by a variety of specialists and therapists and many receive therapies at their school.
Table 4. Special Health Care Needs/Disabilities of the Children

<table>
<thead>
<tr>
<th>Primary Special Health Care Need or Disability</th>
<th>Frequency</th>
<th>Secondary Special Health Care Need or Disability</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td>15</td>
<td>Speech/language disorder</td>
<td>9</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>10</td>
<td>Epilepsy, seizure disorder, West syndrome</td>
<td>8</td>
</tr>
<tr>
<td>Down Syndrome/Intellectual Disability</td>
<td>9</td>
<td>Asthma</td>
<td>6</td>
</tr>
<tr>
<td>ADHD</td>
<td>9</td>
<td>Stomach disorders</td>
<td>3</td>
</tr>
<tr>
<td>Neurological disorders</td>
<td>8</td>
<td>Heart disorders</td>
<td>2</td>
</tr>
<tr>
<td>Mental health disorder</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deaf/hard of hearing</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blind/visually impaired</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sickle cell anemia/methylmalenonic acidemia</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain disorders</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spinal disorder/spinal muscular atrophy</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rett’s syndrome</td>
<td>2</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

OVERALL FINDINGS

Three major topic areas emerged from the analysis of the texts:

1) Care coordination  
2) Family-centered care  
3) The role of race/ethnicity on the patient-provider relationship

For the purposes of the analyses, care coordination is defined in terms of a) health care providers referring parents to medical and support services in the community; b) health care providers providing parent education; and c) interdisciplinary communication. Family-centered care is discussed in terms of a) the extent of time spent with doctors; b) the quality of parent-health care provider communication; c) parent-health care partnering; and d) family sensitivity. Each of these topics is explored, with quotes from focus group participants to illustrate findings. The role of race/ethnicity is discussed in terms of a) health care satisfaction; b) parent-health care provider relationships; and c) preference for same-race health care providers. Quotes
from parents are included to illustrate a point. For the most part, few differences were observed between male and female focus group participants or between the areas or sites of the focus group meetings. Cases in which there was a difference between Latino and African American parents are noted.

1. CARE COORDINATION

To understand the extent to which participants receive some level of care coordination, the concept of care coordination was operationalized to include a) health care providers referring parents to medical services in the community; b) health care providers referring parents to support services in the community; c) health care providers educating parents about the child’s disability; d) health care providers communicating with each other on the child’s health issues and treatment. Each of these topics is discussed, based on the responses to the following questions asked during the focus groups:

- Does your child’s doctor tell you about other resources in the community, such as parent training or support groups? If no, how do you find out about other medical services that your child might use? How do you hear about resources in the community, such as parent training or support groups?
- How well does your child’s doctor communicate with other doctors your child sees?
- How well does your doctor communicate with other providers of health care services your child gets, such as speech therapy, occupational therapy, physical therapy, or other medical specialists?
- How much do you think your doctor knows about other health care services and resources in the community that may help your child?
- How important is it that your child’s doctor arranges help for your child’s special health care needs?

Medical Treatment and Health Care Services to Children

The focus group participants confirmed that children with disabilities/special health care needs throughout the Commonwealth of Virginia are receiving an array of health care services. Given that the children of focus group participants must have a primary doctor and be receiving frequent and ongoing treatment, this finding was not surprising. The finding that was surprising is how critical the school system is in helping children access needed services. Schools are seen as an integral component in delivering health care services such as occupational and speech therapy and counseling. Several focus group participants discussed how these school-based services were not frequent enough, and many parents reported that their child was not considered eligible for needed services. However, schools continued to be viewed as an important source in obtaining needed services.
In terms of health care providers providing information about other relevant health care services and treatment, most parents acknowledged that their primary doctor was very helpful in providing referrals to appropriate providers. There was little difference in the experiences of Latino and African American families, little regional difference, and little socioeconomic difference.

“It is always at the pediatric practice, but all the doctors have seen him, all of them are well informed of his condition. So for me, there has never been a single problem if I am not going to have the same doctor because all of them are aware of his condition. And a lot of times they have referred me to services. So, I have had no problems with that.”—Latino parent

While children with disabilities/special health care needs are connected with primary care physicians and appropriate specialists, there emerged three areas of serious concern:

1) Health care providers are often not referring children for behavioral health concerns.
2) Health care providers are not telling parents about Early Intervention.
3) Health providers make an unintentional error in diagnosing the disability or special health care need.

Behavioral Health.

Several parents talked about how they alerted the pediatrician or primary care physician to behavioral issues with their children, but the physician did not provide resources or referrals. One parent observed, “As long as there’s no behavior issues, people will move mountains.” This situation was particularly prevalent among the Latino families, whose concerns for their child’s behavioral health issues were often overlooked. The following quotes highlight how behavioral health concerns were often overlooked.

“He has a moderate ADD, but because it is not a severe case, it doesn’t matter as much to them. They recommend medication and that’s it. So I’m the one who had to look for the therapy with the counselor. I’m the one who asked for an appointment with the psychiatrist, so that way they could see him and I could request something I would like to work on, some issues with him, but I’m the one who is asking for it. Maybe because it is not that severe and you can keep on going with your life with a child with that type of diagnosis, but I would like my child to achieve his maximum potential.”—Latino parent

“J’s diagnosis depends on who are you asking; it depends on the day. Some days he could behave very bad and some other days he could be fine. In some places,
he is considered to have autism and in others mental retardation, so it depends on who you ask.”—Latino parent

“I always had doubts about L. His problems are related to behavior skills and adjustment. He has times where nothing happens, times where everything is normal and times that you don’t know what’s happening to him, but he has never been diagnosed. The truth is that I can’t say what’s going on with him. I’m in that process of learning what it is or at least to know what can I do for him.”—Latino Parent

Similarly, several focus group participants talked about how their child’s autism was often not diagnosed in a timely manner. They recognized that their child was presenting autistic symptoms, but the health care providers did not respond.

“I took him in three times to see three different doctors in the practice. They all said the same thing—‘He is a normal boy.’ Nothing; they didn’t refer me to anybody. When I took him to a psychologist, they examined him and diagnosed him with the condition.”—Parent

“I had to fight with the others to eventually get the doctor to say he’s autistic. I taught kids with autism; I see the traits. [The doctor] is saying, ‘He’s just being three.’”—Parent

Early Intervention.

Another area of potential concern is the limited access to Early Intervention. Among the 54 parents who participated in the focus groups, only four mentioned that their child with a disability or special health care need received Early Intervention. It was not clear how these four parents heard about Early Intervention. Several other parents complained that they were not aware of Early Intervention when their child was younger and that they therefore missed the opportunity to possibly help their child reach developmental milestones sooner. The following comments by parents reflect the lack of referrals to Early Intervention.

“No one was there to say, ‘Be on the lookout for these things at 12 months. Be on the lookout for these things at 24 months. Be on the lookout for these things at 36 months because your child is high risk for these potential disabilities.’ We brought it up. We put him in an Early Intervention program; it wasn’t a referral from a doctor.”—Parent

“I use to say to them, ‘He is not talking; he is not talking’. They never told me about Early Intervention.”—Parent
“When she was three, I signed her up for preschool and the preschool said she doesn’t function like normal children. She needs special attention.” — Parent

Diagnostic Error.

About one-fourth of all the parents who participated in the focus groups identified some type of diagnostic error, typically a delayed diagnosis of autism or hearing loss. These errors were about as prevalent in each area of the state and affected both African American and Latino children.

“They kept telling me about my son, that he was normal. I said, ‘You need to look at his record because he has been in this emergency room a lot. She said, “There is nothing wrong.” I said, ‘I’m not leaving this hospital tonight until you find out what is wrong with my child.’ As soon as they got him diagnosed, he was much better.” — Northern Virginia African American Parent

“There was inflammation in her eye when we took her to the doctor. It was inflammation in the optic nerve on the left eye. The doctor said it should get better in six months. In six months, the left eye didn’t get better. She lost her vision in that eye.” — Northern Virginia Latino Parent

“We started late because he was misdiagnosed. They said he was fine. The doctor said not to worry; he’ll be fine. We found out in a horrible way. I went to pick up some records for the school and read ‘profoundly deaf.’” — Richmond African American Parent

Parent Support Services

Throughout all the focus groups, parents indicated that they do not hear about parent resources in the community through their health care providers. Health providers are often not aware of support resources in the community to help children with special health care needs and are very rarely aware of personal support and training for parents. Parents who found these resources had to locate them on their own or rely on their personal network. Some parents wondered if doctors assumed that the parents know about support services for themselves or their children. The lack of knowledge about parent support services is exemplified through the following quotes.

“The only reason I knew about it is because I’m already a special education teacher, so I already know the information to tell my student’s parents. So now I’m using those resources for myself.” — Northern Virginia Parent

“There wasn’t any support group and there wasn’t a whole heck of a lot of support. My family isn’t here... If you don’t have a personal support network,
there isn’t an organized support network you’re going to be referred to except by chance. I’ve not found that anywhere. I was thinking about starting a support group for dinner just to talk. It’s not easy.”—Richmond Parent

At the same time, a number of families in both of the Tidewater focus groups talked about how Children’s Hospital of the King’s Daughter (CHKD) was helpful in providing resources and linking families together. It should be noted that CHKD is the location of the Hampton Roads Care Connection for Children program. This is a state-funded program designed to provide care coordination and family-to-family support for families of special needs children. Therefore, it is not a surprise that families receiving services from CHKD were more likely to be connected to other families and were pleased with the care coordination services available to them.

“They [CHKD] have like a team of people, because the guy who works with the school system would fax things to the school...They link you to those people, I guess, when you go through the whole thing.”—Parent

“Our audiologist has been wonderful. When he was at CHKD, the time spent was wonderful. They’d come to IEP meetings; that was great.”—Parent

“There’s always bad apples everywhere, but I can’t say enough about CHKD. When we left the hospital, we had the whole kit and caboodle. We had the waiver in place, we had everything in place.”—Parent

“When it comes to things, CHKD makes sure I know everything, about parent meetings and support groups.”—Parent

“I agree with you too, that CHKD is the best, and I’m originally from New York and I don’t feel that I would have gotten the care for her, up there, like I get down here.”—Parent

“CHKD--I always give them good reports because they have always been thorough in everything I’ve ever dealt with.”—Parent

Despite that many health care providers do not provide sufficient information, family members reported that they are finding out about support services through the school system, other parents, family members, or through searches on the Internet. The following comments show that parents look for opportunities to network with other parents of children with similar special health care needs or disabilities.

“I find we have to network, as parents. Find out what’s going on and that’s how I get my information. When I go to a doctor, I am mainly dealing with the issue at hand, I don't get to that.”—Parent
“I’ve been there, attending groups. I attend groups like I’m on the SEAC⁹ advisory group. I want to know all that I can know and I want to do all I can do for my son and there’s no bridge I wouldn’t cross to be there for him.”—Parent

[I belong to the] “SMA¹⁰ support group. You can be hooked up with a parent of a child or a self-advocate. I linked up with a parent and she was going through stuff I hadn’t yet gone through.”—Parent

The general sense is that some family members are linked in with other parents, primarily through the school system, while most families are isolated. The issues seem to be due more to the lack of resources in the community, lack of outreach and recruitment, or lack of awareness by health care providers than lack of family members being interested.

**Parent Education**

In general, parents report that health care providers are often not providing parents with the information they need about their child’s disability or special health care needs. Parents described how badly they need to be informed about the disability/special health care need and how important it is that they are knowledgeable. They report feeling overwhelmed by wanting adequate services for their children, but not having sufficient knowledge about the special health care need or disability. The overall sense is that parents are receiving appropriate treatment for their child’s disability/special health care need, but parents are missing the overall picture of what it means to have the disability/special health care need and how to navigate the health care system.

The process of finding information that is useful and relevant to their child and to the child’s situation has been difficult, but the parents expressed resolve and commitment to learning all they can, as reflected in the following comments.

“I’m like this, I want to know all that I can know, and I want to do all that I can do for my son. It’s nothing that I wouldn’t go [to] or no bridge that I won’t cross to be there for him.”—Parent

“S was given a diagnosis on January 17, 2007. She was three at that time. So, ever since, we’ve been trying to be active, learn as much as possible about her

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⁹ Special Education Advisory Committee, a committee comprised of parents and volunteers appointed by local school boards.

¹⁰ Spinal Muscular Atrophy
disability and how it affects her. I’m pretty much trying to learn everything I can to help her.”—Parent

Focus group participants often expressed how much they would have wanted health care providers to give them more information about the disability or special health care need, or to steer them in a direction in which they could obtain more information. Participants tended to explain that the reasons for not getting more parent education from health care providers was due to health care providers either inadvertently withholding information or not being knowledgeable about the disability or special health care need.

Some parents mentioned that health care providers will respond to questions and specific concerns, but they are missing important pieces of information. As the following comments suggest, they are looking for greater awareness of the disability/special health care need in addition to specific information that could benefit their child.

“They will give you that when you ask for it. But it’s the thing that they don’t offer. We can request stuff all day, we can tell them stuff we want all day, but it’s the stuff that we don’t know, that we need to ask for. The stuff that we don’t know that we can ask for, that’s the issue.”—Parent

“I feel like they tell you what you ask them. It’s not often they go to offer you information that you don’t have. If you ask them a question, they’ll answer it. But, if you don’t go there with the information that you’re looking for, or the questions you need to ask them, it’s not like they’re going to offer anything new.”—Parent

The difficulty in learning more about the disability/special health care need seems to be more pronounced among the Latino parents and the parents whose children have autism. Several Latino parents seemed to be getting the vast majority of their information through the Internet, through the school system, or by happenstance. Parents of children with autism seemed to particularly struggle finding information, though their interest in parent education is very high.

“I have a seventeen year old boy who has autism, for three or five years. It has been very difficult for me to find a very good psychiatrist. I am still fighting.”—Latino Parent

“With an autistic child, the doctors don’t know what’s going to happen...Autism is like an umbrella; it affects many things where Rett syndrome is one specific thing. So my husband is more laid back and I’m more the one who is always on the phone. I’m advocating for my son because if I don’t, it’s nobody. It doesn’t matter if it bothers them, I’m going to look.”—Latino Parent
The health care provider’s lack of knowledge about the disability/special health care need can have some detrimental consequences to the child. As shown in the following examples, some of the parents revealed that their physicians are uninformed about special health care needs and disabilities.

“But as far as a pediatrician, he doesn’t know anything; he doesn’t understand kids with cochlear implants. It’s very much in and out. With his processor, it’s dangerous if he has an ear infection. His body could attack his processor, so I need an appointment quickly. We have to go to Patient First. They don’t get it because they don’t have the experience of working with cochleas.” — Parent

“There should be information training on disabilities and they should be more in tune with parents who have children with disabilities. Like, my son has a weight problem and they want me to develop my plan. My son will have all these behaviors but you’re not telling me how to do the plan and deal with the behaviors. If you’re going to tell me what to do medically, you need to tell me how to deal with the disability.” — Parent

“I noticed that some doctors [are generalists] and they don’t know anything else...I’ve been through many things that I should not have because many times they just guess, because that is not their specialty.” — Parent

Interdisciplinary Communication

In general, parents indicated that their children’s specialists and generalists communicate with each other, informing each other of treatment and diagnoses. The disconnect arises, though, in interdisciplinary collaboration. Parents expressed their concern that health care providers do not collaborate and that their children’s disability or special health care need is approached through fragmented, symptom-specific ways. In response to the question, “How important is it that your child’s doctor arranges help for your child’s special health care needs?, nearly all the parents indicated that it was very important.

“I would like to have a better doctor, a pediatrician who would manage everything. Like I said, I come from New York and there, her pediatrician used to manage everything. They used to say, ‘You have an appointment for a specific day [for the specialist] and they hand me a paper with the appointment...I didn’t have to make the appointment.’” — Parent

Some parents indicated they want better collaboration between the school system and health care providers so that adequate school services are in place.

Many of the parents expressed feelings of being overwhelmed by having to do the care coordination themselves. They stated that they do not have enough disability/special health
care need knowledge; they do not know what services are needed or how to find them; they do not know the best health care providers; they are inundated by the complexity of the health care system and health insurance. Parental care coordination can be challenging when there are language or educational barriers, when health care services are not available, or when the parent has insufficient social supports, as reflected in the following comments.

“I am the one who picks up the phone to call the doctors; I am the one who is setting up the visits for the medication. I do almost everything. Sometimes I don’t have the help from the nurses. ...I need a little help because it stresses me out. Sometimes I can’t sleep and with the complications she already has. She has had a tracheotomy and she has Down’s syndrome and sometimes that disrupts the night because I am waking up or sometimes I can’t find the nurses.”

“I am my child’s full time case manager and I work full time and I go to graduate school. Dealing with the doctors is the hardest part because now I’m going in circles. And I am tired.” -- Parent

“If there’s going to be a team of doctors, honestly, the only way to do that is if the parent is the captain of the team. Where that breaks down is when the parent doesn’t have the ability to synthesize that information, doesn’t have that knowledge to draw their own conclusions from it. Just because you’re a parent, you don’t have all the knowledge you need for a special needs child.” -- Parent

“It was difficult in the beginning. When we moved to Virginia, we couldn’t find a dentist who would deal with kids with autism, because you don’t want to have your child strapped down on the dentist chair. I got my child on medicine, but medicine without support is not helpful. I couldn’t find a psychologist. I called the CSB because he was being seen by Early Intervention and the assistant director answered the phone and she said she’d get me some help. I had to be my own case manager. Trying to keep appointments and have everything planned, and be sure the referrals were made. Everything was hard.” -- Parent

2. FAMILY-CENTERED CARE

Family-centered care was operationalized to address four main areas—a) extent of time spent with doctors; b) parent-health care provider communication; c) parent-health care provider partnering; and d) family sensitivity. Each of these topics is discussed, based on the responses to the following questions asked during the focus groups:

- In general, does your child’s doctor spend enough time with you at appointments? How do you think this affects your child’s treatment and special health care needs?
- How well does your child’s doctor communicate with you?
• How well does your doctor listen to your opinions and what you have to say about your child?
• How well does your child’s doctor consider or understand your values and your culture when providing health care?
• How well do you feel you and your child’s doctor are working together as partners?
• Are there ways your child’s doctor could be more helpful to you and your family?
• What do you like best about what your doctor does?

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**Time with Health Care Providers**

When asked, “Does your child’s doctor spend enough time with you at appointments?,” about half of the African American parents responded that the doctors spend enough time.

“My son’s developmental pediatrician, she always spends an hour with us. We drive to Rockville, Maryland, which is pretty much an hour from my house. The reason I do that is the first time I met her, we built a rapport. I appreciated this. She spent an hour with me. Ever since, each time it has been an hour.”—African American Parent

In contrast, all of the responding Latino parents indicated that the doctors do not spend enough time.

“In my case the psychiatrist writes down the prescription and he doesn’t spend enough time with you, like a mental health problem was just a matter of medication.”—Latino Parent

“In my case, my pediatrician does not spend time with me, maybe just three minutes. My daughter use to be scared of doctors; she use to cry from the beginning ‘til the end...They wanted to finish the appointment soon.”—Latino parent

Some parents described examples of how the length of time spent with the doctor can have a significant impact on the child’s health care.

“I have often felt like saying, ‘No, don’t give this medicine to my child because this medicine has such a side effect and this medicine does this and this to my child.’ But the doctor doesn’t take the time to know what I have to say about the side effects of the medicine he wants to prescribe.”—Parent

“My son being on an autism spectrum, it takes him a while to get used to the room, warm up to people. When they take the time, to be with us, they are also taking the time to be with him. He realizes that. So when she is finished talking
with us and it's time to examine him and we've been there for while, and he's gotten used to the place, he is more receptive to letting her look into his ears and eyes and talk to him. He knows that if you are taking time with my parents, you are taking time with me. That is better for him.”—Parent

Parent-Health Care Provider Communication

There were numerous comments from the focus groups about both good communication with doctors and other health care providers as well as poor communication with them. In terms of good communication, a number of common elements surfaced:

1) The doctor/provider promotes an open dialogue prior to making a diagnosis
2) The parent comes prepared with lists of questions or concerns
3) The doctor/provider offers empathy and information
4) The doctor/provider initiates some type of follow-up
5) The child with a disability or special health care concern feels engaged and comfortable
6) The parent feels that her concerns are being acknowledged, particularly if the concerns are urgent
7) The doctor/provider provides individualized attention to the child; i.e., the doctor views the child as a unique individual instead of as symptoms to be treated

Several commented that the availability of the doctor was also helpful, particularly if they were able to communicate by email. Among the parents who primarily speak Spanish, good communication included having an interpreter who can accurately relay the intent of the parent.

In general, about half of the focus group participants, both Latino and African American parents, indicated that the communication with their child’s doctor is good.

“From the beginning, she [the doctor] was very concerned...She talks, she calls.”—African American Parent

“We come in and she sits down and talks. M seems to like her. There are some doctors she’d go to and she’d pretend to fall asleep.”—African American Parent

“I felt extremely lucky to have the help that I have had. The doctors have given me a lot of support and through it, knowledge of the state of my child.”—Latino Parent

“Now the new doctor is a lady that is older. She is very accommodating and we always like to go there. As time goes on, they’re feeling comfortable. Why change doctors if the children are feeling comfortable. In the neurologist’s office,
there’s only one doctor and he makes you feel comfortable and he lets me know what’s going on and what’s happening. Well, we won’t worry about it then. He communicates with me.”—Latino Parent

However, more parents discussed communication that was dismissive or disrespectful than good communication. The focus group participants revealed several common themes that are associated with poor communication between the parent and doctor. These include:

1) The parent feels rushed to leave the doctor’s office
2) The doctor/provider ignores the parent’s observations of the child
3) The parent feels dismissed
4) The parent feels that they have to demand services
5) The parent feels that the doctor cannot be trusted
6) The doctor/provider is uninformed about the disability or special health care need
7) The doctor/provider does not provide sufficient information or potential resources
8) The doctor/provider does not provide clear instructions on office procedures and patient expectations

The outcomes of poor communication were more apparent than the outcomes of good communication. Parents complained of feeling frustrated and stressed by the poor communication, but many explained how miscommunication and misinformation can be damaging.

“Everyone has different opinions. In my case, it is that way. And every time that I leave the doctor’s office, I leave half angry and half wondering, what I have done. But I always know it is going to be that way and I always feel that’s because he is autistic. I don’t leave satisfied.”—Latino Parent

“My son’s first pediatrician, when he was born, wouldn’t listen to me. He blamed everything on me being a first time mom. I went to him at six months; ‘I think my son isn’t rolling over’. I went to him at nine months; my son isn’t sitting up. I mentioned that he isn’t trying to crawl. He said, ‘You are just a first time Mom; you are so worried.’ So at 13 months he was finally diagnosed with having Down Syndrome, something that is diagnosed when you are first born.”—African American Parent

“I worry that when I bring my daughter in, because she has autism, it takes her a while to get acclimated. When I’m seeing a new doctor for a quick visit, they make too quick judgments of her behavior without understanding that she’s nervous. She’s not always this way. This last lady I saw, she said we can give her drugs for anxiety. I just thought, we are already on enough drugs. Let her relax for a minute and she’ll be fine. That’s what concerns me--the push with medications.”—African American Parent
Most of the parents in the focus groups indicated that they do not feel that they are in partnership with the health care providers in managing the disability or special health care needs of their children. Some parents reported that they have to take charge, remind the doctor of lab work to be scheduled or reiterate their concerns.

“I had to go back to him to ask him again and this is what I’m running into. If we’re in the office for a visit and I’m asking him about a new symptom, it’s like it goes in one ear or out the other. I don’t know if he didn’t hear me or if he’s busy concentrating on one thing or another.”— Parent

“I have to explain the whole situation each time I go. I have to explain about all the medication.”— Parent

The comments that many parents made suggest that they have serious issues of trust with the doctor or health care provider, professionals who are integral to the care and well-being of their children with disabilities or special health care needs. The lack of trust not only hurts the patient-health care provider partnering together, it can lead to the child not receiving treatment. Seven parents in the focus groups suggested that the reason they discontinued treatment or changed providers was due to the lack of parent-provider trust.

“I feel very apprehensive towards the doctors. I go to the check-up and that’s it. If I have questions, I’m not even interested in asking him. That is why I’m still in this process where I can’t find a doctor.”— Parent

“I got so stressed, my muscles were so tight. She said, ‘You need to calm down.’ That was the last time I went there.”— Parent

“So when I come to my appointment I just want the check up and leave. I still feel that I don’t have any trust in them.”— Parent

Surprisingly, many parents who participated in the focus groups stated that the process of accessing adequate treatment for their children was actually contentious. They often used the word “fight” to describe the process they had to utilize to obtain health care services and they portray an adversarial relationship between the family and the health care system. The conflict was typically not between a specific professional and themselves as much as seemed to be anger in response to feeling that their access to services is being denied.

“You can’t accept no for your child. You have to tap into the right person.”— Parent
“I remember when I went to the hearing specialist. He told me what I had to do, so I told him that I already did it. ‘Look at this paper.’ So I said to him, ‘If you cannot put in the ear tubes for him, I can go to another doctor. He has been sick for more than one year and I don’t want him to go through this anymore. Tell me doctor, do you want to do the surgery or not? I’m not going to waste my valuable time, nor yours.’ That’s when I started seeing results.” — Parent

“They don’t help me. I have to push them to get the resources I need.” — Parent

“For me, with the speech therapy, I had problems at first. But I’d call them like every two days because I’m a squeaky wheel... I squeak and squeak and squeak until I get what I want.” — Parent

“I feel as though I have to be stern and aggressive to get the help I need for my son.” — Parent

Parents expressed a lot of anger towards the lack of access to therapeutic services in school. However, these comments are not included because the purpose of the focus groups targeted the health care field, not the educational system.

A number of patterns about family-centered care emerged through the focus group text analysis. Parents are struggling with multiple barriers in obtaining medical treatment and health care that is beneficial to their child with a disability or special health care need and they want to have a better parent-provider relationship and family-centered care. Some of the practices that parents appreciate include the following.

1) Consistency of appointments with the same doctor instead of large practices in which the child might be seen by multiple doctors over time.
2) Access to the doctor through email or telephone
3) Availability of the doctor during emergencies
4) From therapists, written updates on the status of the child and instructions on how to help the child at home
5) Coordination or consultation with the child’s school

The most common suggestions that parents offered for health care providers are 1) to provide better information, 2) to listen to the parent, 3) to treat the child as an individual entity; and 4) to provide more timely referrals instead of adopting a “wait and see” approach. Other suggestions parents offered include the following.
“If it is a good doctor, he would say, ‘Talk to me about her. How is she? How do you communicate with her?’...So then, I say, ‘Ok. I am going to pay attention to the doctor because I know that they are worried about my child.’” — Parent

“To know that the visit, the time that we are taking, whatever we are doing right now, this may be your job, but this is impacting our lives. The way we feel, the way we think what next step we want to take to help our children better themselves.” — Parent

“To have more knowledge. What can you tell me? Instead of just referring, then you wait six months to see the specialist. You’re still banging your head. Tell me something else if that’s all you got. It’s twofold; spend more time with me but can you set aside 30, 45 minutes to figure out what to do to help my family?” — Parent

“For me, I just would like to have my appointments arranged, instead of giving me the paper. So that way I don’t have to call and find an interpreter.” — Parent

One of the most prevalent themes throughout the focus groups is that parents need for providers to recognize and respect their observations of their children. The focus group participants often complained that doctors and other health care providers often dismiss the parent’s concerns or intuition, particularly if the parent is concerned about the child’s behavior. The parents suggest that greater partnering with health care providers can be achieved when health care providers acknowledge that parents have significant knowledge, insight, and intuition about their children and their perspectives need to be respected.

“You’re more knowledgeable about the disability your child has. I have to ask ‘Do you know about Rett syndrome?’” — Parent

“I just wish they would just listen. Just listen, I’m trying to tell you something. You see my children when I bring them in. That is the only time you are in contact with them. I’m with them every day. I see what goes on, I see what happens if you would just listen. We wouldn’t have a problem. Don’t cut me off.” — Parent

“I didn’t get a whole lot of help. We were in Virginia Beach with an older doctor; we needed a referral for everything. ‘Just wait for the next appointment. He’ll be fine.’ But I think a parent knows. You may not know what you know, but you know. You know something is going on. As a parent, you know. To continue to make appointments with the doctor and they keep saying to wait, you feel powerless. To feel like you are beholden to the doctor to make a referral is powerless.” — Parent
“I want a doctor that will listen to you. He will tell me, ‘You are with this child all the time, so I want to hear what you have to say.’ That makes you feel good. If they don’t know what they’re talking about, I have to move on. You have to tap into the right person.”— Parent

“You can see a child for 50 minutes, but I come with a whole report of a week, of a month, of day by day. Listen to me. I give you the information that you need to prescribe or understand what is going on. They need us.”— Parent

“One time she had an ear infection. I wanted them to wrap him in a sheet. The doctor said ‘I know what I’m doing.’ It takes ten people to hold him down; what makes you think you shouldn’t wrap him in a sheet?”— Parent

3. THE ROLE OF RACE AND ETHNICITY

The role of race/ethnicity is discussed in terms of a) preference for same-race health care providers; b) cultural sensitivity; c) health care satisfaction; d) parent-health care provider relationships; and e) the role of language in family-centered care. Each of these topics is discussed, based on the responses to the following questions asked during the focus groups:

- Is your child’s doctor of the same race or ethnic background as you? Do you think this is important?
- What is your reaction to these statements?
  - Latino/African American families are less satisfied with the health care of their children than are white families.
  - Doctors and nurses often disregard what Latino/African American parents say.
  - Latino/African American parents of children with disabilities have more trust in health care providers of their own race or ethnicity.
- How well does your child’s doctor consider or understand your culture when providing health care?
- Do you think that being African American/Hispanic affects the care your child receives?
- (For Hispanic families) Do you use an interpreter when you visit the doctor? How well does this work?

The Importance of Same-Race Health Care Providers

Focus group participants indicated that in some cases, the health care providers share their same race/ethnicity, but this is typically not the most important quality parents seek when making decisions about health care providers. In general, the focus group participants
indicated that their level of comfort is higher among a provider of the same race, but their focus is more on the provider’s skills than the provider’s race.

Several factors play a role in choosing a health care provider, such as location, rapport, health insurance coverage, specialty, and references from families, friends, or other doctors. Most parents commented that the doctor’s race/ethnicity was unimportant. Similarly, most disagreed with the statement that Latino/African American parents of children with special health care needs/disabilities have more trust in health care providers of their own race or ethnicity, indicating that either they have limited experience with same-race providers or they have had trusting relationships with doctors of other races.

“Race doesn’t matter. If you are green or half man, half animal and you can provide the services you need, that’s what matters.”— Parent

“No. Nothing but the best.”— Parent

“I see both. For me, the most important thing is to have connection with them, that they’ll return my calls. I don’t care about their race or their gender.”— Parent

“I haven’t found an African American physician, counselor, psychiatrist has ever brought anything more to the table. I don’t like the preconception that we have something in common just because we are black. We might; we might not. It’s not a positive for me.”— Parent

“As long as they take care of our children, it doesn’t matter. The only thing is with a Hispanic background, you feel more relaxed.”— Parent

“It doesn’t matter as long as they can treat your daughter with dignity and respect.”— Parent

For many, however, the race of the health care provider matters for a number of reasons; for example, parents have a higher level of comfort and rapport, and that same-race providers are more aware and respectful of cultural traditions and practices. Some Latino parents commented that Hispanic doctors are more demonstrative and friendly. Some African American parents commented that Caucasian doctors seem more easily threatened. While these reasons may not affect the parent’s decision-making process in choosing a health care provider, they do seem to affect the level of family-centered care.

“I had doctors saying to me, ‘I’m not used to be questioned.’ They would say to me, ‘I know you and your husband are intelligent people, but I’m not used to be questioned.’ I was shocked. I read that to mean, ‘I’m not used to black people asking me what I’m doing.’”— Parent
“I have said that I wanted to talk with the nutritionist to see if I could make real food for my child, like I did in Mexico where I made the food and I gave it to him. But it seems to me that here they don’t permit it. So then, I am desperate. What should I do: stay here or is it better for me to go back to my country? I need help, so that he can benefit.”— Parent

“I have found American doctors to be more reserved; they build walls around them. They won’t let them down for other people. But Hispanic doctors deal with the friendship, the relationship. They have the freedom to speak and they speak in depth about a problem or building a relationship.”— Parent

Among the 54 parents who participated in the focus group, only four made a conscious decision to find a health care provider of their own race/ethnicity. Two of these parents are African American; two are Latino.

“I sought one out. It’s important because Dr. J is going to know more about my social issues and will know the barriers I face as an African American man. There’s more of a chance I can identify with him. The social dynamic does play a role when you deal with a professional of the same race. I can say that without ambiguity or without hesitation because I’ve faced it. I’m ok with working with a doctor who is white or Asian. I sought that out for my own comfort.”— Parent

“I have found a Cuban doctor. It’s important because he shares my culture. To me, it’s important to listen to him because he will come up with home remedies and the doctors will understand and accept them, because of our culture. When I will call him and ask about things, he will get me things that he knows our culture will accept as remedies. I didn’t have to explain to him my decisions because he understands and we both spoke at the same level. That was one of the reasons I chose him.”— Parent

Cultural Sensitivity

A key component in developing family-centered care is the health provider’s ability to respect cultural diversity, recognize the importance of cultural practices and traditions, and a willingness to learn about cultural practices. When focus group participants were asked if doctors and nurses often disregard what Latino/African American parents say, most agreed. Some of the parents cited specific instances in which their opinions or concerns were discounted and others spoke of more pervasive attitudes. In some cases, the sense of feeling disregarded was obviously connected to their race/ethnicity, but most of the time, the feeling was more intuitive. Some of the parents felt the lack of cultural sensitivity was compounded by their income, having Medicaid, or being in a less affluent area of the state. The feeling of being disregarded was common among both African American and Latino families.
“This new psychiatrist, he’ll try something and he didn’t read the records that show all the medications that didn’t work. Sometimes it’s because I’m black. That’s my last thought, but I get there. So I think, ‘Why are you being so dismissive?’”—Parent

“What happens to me is that sometimes they are too friendly and when they listen to me and see my appearance, they don’t think I am Latino and they ask, ‘Where are you from, France?’ Or when you say you are from Argentina, where we speak Spanish, there is something up in the air. That has happened to me.”—Parent

“My son, when I have done home remedies on him, he is embarrassed because we go to an American doctor and they think I am crazy but if we went to a Hispanic doctor, he would know about home remedies.”—Parent

Given that most parents indicated that they can trust providers of a different race and the race of the provider is unimportant, it was surprising to hear that most felt that their opinions and observations are disregarded. The issue may be a lack of reciprocity—that the focus group parents feel trust towards providers while receiving, and expecting, less in return. Also, there are many more Caucasian than African American or Latino doctors and perhaps parents have resolved to establish a good parent-provider relationship, necessitating parents overlooking their own wariness in exchange for trying to achieve the best care for their children. The other issue may be a reluctant acceptance by parents of large-scale but subtle cultural insensitivity and racial discrimination.

Health Care Satisfaction

In response to the statement, “Latino (or African American) families are less satisfied with the health care of their children than are white families,” a small majority agreed. The others were mixed between disagreement and being neutral. Those who indicated a lack of satisfaction focused on not hearing about available resources or not having resources available in their community. “Well, we don’t get the same services they do. It’s not equal across the board,” said one mother. “It’s not the services, it’s the quality. We don’t know about the services,” said another parent.

“It was a definite discrepancy. When the doctors ask me for my child’s name and the child couldn’t answer, they tag him as mentally retarded but it’s not that he doesn’t know his name, he doesn’t know the English and his name.”—Parent

“I believe the American families have better services than Hispanics. I went to the ophthalmologist with my child and I had arrived before my appointed time.
My experience with the doctor was that I got there, I signed in and the nurse at the front passed everyone who was before me, and after two hours, when I thought she would call me, a woman walked in and said ‘I don’t have an appointment but I need the doctor to see my child’ and they passed her on before me even though I had an appointment.” — Parent

Parent-Health Care Provider Relationships

Because parents reported less satisfaction with health care and feeling disregarded by providers due to issues of race/ethnicity, it was not surprising that most parents indicated that they feel that being African American/Latino affects the care their children receive. The majority responded to the question, “Do you think that being African American/Hispanic affects the care your child receives?” with “yes.” There was little difference between African American and Latino focus group participants.

The basis for parents feeling that race/ethnicity affects their children’s care seems to be derived from experiences related to health care access and cultural sensitivity. Parents also identified that having a low income, receiving Medicaid, or speaking Spanish added to the feeling that race/ethnicity affects the care their children receive.

“[There is a] mentality of discrimination against the special needs children of Hispanic people. There is more discrimination against Hispanic people who have children with disabilities. They look at them like a strange bug when they see them in a wheel chair.” — Parent

“Let’s not forget where we are. I mean, I’m from New York, so up in New York, it’s really about the money, but down here it’s about, to me, the color. We’re in the South.” — Parent

The Role of Language in Family-Centered Care

Among the Latino focus group participants, one spoke only English, most spoke only Spanish, and the remainder are bilingual. Those who speak exclusively Spanish use interpreters when interacting with health care providers and all indicated that the hospital made interpreters available to them if they did not have one of their own. Some used family members, including children, to provide interpretation and at least one had to pay for interpretation services out of pocket.

Parents expressed a number of problems with interpreters thoroughly representing their messages. As a result, parents were often left confused and providers were unable to fully understand the child’s situation. Some parents seemed to strongly prefer to use limited
English to convey their concerns about their child rather than use an interpreter. In many cases, the health care provider would insist on an interpreter over talking to a parent with limited English.

“It is not the same and she couldn’t translate and what the child was doing at that moment, I could have explained everything to her but she wanted to hear the interpreter.”-- Parent

“The problem with interpreters is that one word is meant differently in all these different countries. There are so many interpreters. They have learned Spanish in Miami and may not know the correct interpretation of the word. They don’t understand Peruvian or Chilean or Dominican translations.”-- Parent

At the same time, many of the Latino parents stressed how important it is to them to maintain their cultural heritage and have their children fluent in both English and Spanish. None expressed a reluctance to learn English, but many parents expressed the value of having both English and Spanish spoken in the home.

CONCLUSIONS

In conclusion, three major topic areas emerged from the analysis of the texts—care coordination, family-centered care, and the role of race/ethnicity on the patient-provider relationship. Care coordination was discussed in terms of health care providers referring parents to medical and support services in the community, health care providers providing parent education, and health care coordination and interdisciplinary communication. Family-centered care was discussed in terms of the extent of time spent with doctors, parent-health care provider communication and partnering and family sensitivity. The role of race/ethnicity was discussed in terms of health care satisfaction, parent-health care provider relationships, and preference for same-race health care providers. To summarize, the study revealed the following findings:

- There is a limited amount of care coordination by health care providers. A specialist often becomes the primary doctor for children with special health care needs/disabilities. This specialist will often arrange appropriate referrals and have communication with other specialists, except in the areas of behavioral health and Early Intervention.

- Children are often not referred to Early Intervention and behavioral health specialists. Parents’ voiced concerns to doctors about their children’s behavior while the health care provider had a more “wait and see” approach. Children with autism often had a delayed diagnosis.
• Parents rarely learn about parent support services or support groups through health care providers, except for those parents who receive services at Children’s Hospital of the King’s Daughter in Norfolk.

• Parents often express feeling overwhelmed and wanting more parent education about the disability or special health care need of their child, but they receive little information from health care providers. Some parents indicated that the health care provider may respond to questions they have, but they often do not know what to ask.

• The pediatrician or primary care physician often knows little about the disability or special health care need.

• Parents take responsibility for most of the care coordination and often have to educate health care providers about issues related to their child’s disability or special health care need. Parents’ managing the care coordination becomes a daunting challenge when they have insufficient knowledge, or when there are language or education barriers, or when community health services are not available.

• Despite the fact that parents find care coordination by health care providers to be very important, there is little interdisciplinary collaboration and children are treated for specific symptoms instead of holistically.

• About half of the African American parents and all of the Latino parents of children with disabilities or special health care needs felt that doctors do not spend enough time with them.

• While many parents reported having good communication with their health care provider, most felt the communication was often dismissive or disrespectful. Several felt that providers ignore the parent’s observations of the child and that they have to make demands in order to get needed services.

• Most feel they are not in partnership with their health care providers, though they would like to have a better parent-provider relationship and more family-centered care.

• The most common suggestions that parents offered for health care providers are to provide better information, to listen to the parent, to treat the child as an individual; and to provide more timely referrals instead of adopting a “wait and see” approach.
• The race or ethnicity of the health care provider is not an important characteristic parents consider when choosing health care providers, though having a health care provider of the same race/ethnicity can create a greater sense of comfort. Most parents indicated that their level of trust in a provider is not affected by the provider’s race.

• Most parents indicated that health providers disregard them due to their race or ethnicity. The feeling of being disregarded due to race seemed more intuitive, though, than an overt racial bias.

• A small majority of parents agreed that Latino and African American families are less satisfied with the health care of their children than are white families. The lack of satisfaction is primarily due to not hearing about available resources or not having adequate resources in their community.

• Most parents feel that being African American or Latino affects the care that their children receive. The basis for this feeling stems from issues with health care access and cultural sensitivity.

In conclusion, results from the 54 parents find that care coordination from health providers is largely absent, but does not seem to be a result of racial discrimination or bias. On the other hand, parents recognized that elements of family-centered care, particularly the level in which they feel heard by health care providers, may be affected by their race or ethnicity. Most of the parents reported that health care providers spend insufficient time with them and that health care providers often disregard parents’ concerns. Feeling heard by health care providers does not translate into preferring a doctor of the same race/ethnicity or establishing trust in relationships with health care providers.

Model 1 summarizes the major themes derived from the focus groups. The model indicates that from the parents’ perspective, the attitudes, awareness, behaviors, and communication from health care providers has a strong impact on the level of care coordination and family-centered care. At the same time, social and community factors influence health care providers, family-centered care and care coordination, as well as the outcomes to families of children with health care needs and disabilities. Better family-centered care and care coordination can impact both parents and children with disabilities/special health care needs in terms of the family’s engagement and the child receiving optimal care.
Model 1. The Perspective of African American and Latino Parents

Social and Community Factors

**Health care providers:** availability of specialists, interpreters, and bilingual providers

**Social supports:** parent education and parent support

**Health system:** practices of collaboration, interdisciplinary education, family-centered care and care coordination

**Social system:** racial discrimination, cultural sensitivity, cultural awareness, racial/ethnic diversity, health care disparities

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**Health Care Providers**

- **Attitudes of race/ethnicity:**
  - Acceptance of health treatment practices
  - Cultural & language sensitivity
  - Cultural awareness

- **Awareness:**
  - Parent resources
  - Disability-specific information
  - Community services & supports

- **Communication with parent:**
  - Sufficient time
  - Empathy and respect
  - Individualized care
  - Clarity of expectations

- **Behaviors:**
  - Referrals for behavioral health
  - Referrals to Early Intervention
  - Diagnostic accuracy
  - Interdisciplinary communication
  - Parent education

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**Parent-Provider Relationship**

- **Care Coordination:**
  - More appropriate health care services
  - Greater parent supports
  - More parent education
  - Better health care coordination
  - Better interdisciplinary collaboration

- **Family-Centered Care:**
  - Better provider-parent communication
  - Fewer educational, and knowledge barriers
  - Fewer language barriers
  - Greater compliance with doctor's instructions
  - More willingness to see provider
  - Better parent-provider partnering
  - Less willingness to terminate or change providers
  - Increased trust in provider

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**Families of Children with Special Health Care Needs/Disability**

- **Child:**
  - Individualized treatment
  - Effective health care
  - Appropriate health care
  - Willingness to see providers
  - Continuity in health care
  - Engaged in health care

- **Parent:**
  - Greater knowledge
  - Informed decision-making
  - Decreased isolation
  - Engaged in health care
  - Less frustration with providers
  - Less caregiver stress
  - Greater trust of health system
APPENDIX A: FOCUS GROUP QUESTIONS
Parents of Children with Special Health Care Needs

Focus Group Questions

1. Tell me about your child’s disability or special health care need.
   a. What type of disability or special health care need does your child have?
   b. What types of health care services do you use most often?

2. Do you have a regular doctor or healthcare provider who helps you get other medical services for your child (for example: counseling, physical or occupational therapy)?
   a. Is this a doctor or someone in the doctor’s office, like a nurse?
   b. Is this a pediatrician, family doctor or some kind of specialist?
   c. Is this person the healthcare provider you see the most often?
   d. Do you see the same doctor each visit? Or is the doctor part of a group practice where you see a different doctor each visit?
   e. Does your child’s doctor tell you about other resources in the community, such as parent training or support groups?

   IF NO:
   • How do you find out about other medical services that your child might need?
   • How do you hear about resources in the community, such as parent training or support groups?

3. How well does your child’s doctor communicate with other doctors your child sees?
   a. How well does your doctor communicate with other providers of health care services your child gets, such as speech therapy, occupational therapy, physical therapy, or other medical specialists?
   b. How much do you think your doctor knows about other health care services and resources in your community that may help your child?
   c. How important is it that your child’s doctor arranges help for your child’s special health care needs?
   d. What do you like best about what your doctor does?

4. In general, does your child’s doctor spend enough time with you at appointments?
   a. How do you think this affects your child’s treatment and special health care needs?
5. How well does your child’s doctor communicate with you?
   a. How well does your child’s doctor listen to your opinions and what you have to say about your child? Can you give some examples?
   b. How well does your child’s doctor consider or understand your values and your culture when providing health care?
   c. How well do you feel you and your child’s doctor are working together as partners?

6. Are there ways your child’s doctor could be more helpful to you and your family? Please give examples.

7. For Hispanic families: Do you use an interpreter when you visit the doctor? How well does this work?
   a. [For those using interpreters] Who is the interpreter—a family member, someone provided by the doctor’s office, or someone else?

8. Is your child’s doctor of the same race or ethnic background as you?
   a. Do you think this is important? Why or why not?
   b. Do you think that being African American/Hispanic affects the care your child receives?

9. What is your reaction to these statements? [These statements are derived from research findings.]
   a. Latino (or African American) families are less satisfied with the health care of their children than are white families.
   b. Doctors and nurses often disregard what Latino (or African American) parents say.
   c. Latino (or African American) parents of children with disabilities have more trust in health care providers of their own race or ethnicity.
RESEARCH SUBJECT INFORMATION AND CONSENT FORM

TITLE: Health Disparities Focus Groups

VCU IRB NO.: HM12715

SPONSOR: Partnership for People with Disabilities, Virginia Commonwealth University

This consent form may contain words that you do not understand. Please ask the study staff to explain any words that you do not clearly understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

PURPOSE OF THE STUDY

The study is based on findings that African American and Hispanic families are not satisfied with the health care services of their children with special needs. We want to find out about families’ experiences and opinions.

You are being asked to participate in this study because you are of African American or Hispanic descent and have a child with special health care needs.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

If you decide to be in this research study, you will be asked to sign this consent form after you have had all your questions answered and understand what your participation in the study involves.

If you agree to participate and you are eligible, you will be part of a discussion group. The discussion (focus) group will last between 60 and 90 minutes. The focus group leader will ask you to talk about your experiences and opinions about health care for your child. The focus group will be tape recorded so we are sure to get everyone’s ideas, but the transcripts of the tapes will only use pseudonyms (a substitute for your real name).

RISKS AND DISCOMFORTS

We do not expect any risks to you. You do not have to talk about any subjects you do not want to talk about, and you may leave the group at any time. Your participation in the focus group does not affect the health care services of you or your child.

BENEFITS TO YOU AND OTHERS

You may not get any direct benefit from this study but the information we learn from people in this study may help us improve health care for children with special needs.

Please be aware that the investigative team and the University receive funding for the conduct of this study.

COSTS

There are no costs for participating in this study other than the time you will spend in the group and filling out a form.
PAYMENT FOR PARTICIPATION

You will receive a $100.00 check in appreciation for your participation in the focus group. A check for $100.00 will be mailed to you after the focus group.

ALTERNATIVES

The alternative is to not participate in this research study.

CONFIDENTIALITY

Potentially identifiable information about you will consist of focus group notes and audiotape recordings. Data is being collected only for research purposes. Your data will be identified by pseudonyms, not real names, and stored in a locked research area. All electronic personal identifying information will be kept in password protected files and these files will be deleted within one year. Other records (the payment receipt form and this Informed Consent form) will be kept in a locked file cabinet indefinitely. Access to all data will be limited to study personnel. A data and safety monitoring plan is established.

We will not tell anyone the answers you give us; however, information from the study and the consent form signed by you may be looked at or copied for research or legal purposes by the sponsor of the research, or by Virginia Commonwealth University.

What we find from this study may be presented at meetings or published in papers, but your name will not ever be used in these presentations or papers.

The group sessions will be audio taped and the tapes will be transcribed. The transcribed report will not contain any identifying information. The audiotapes and notes will be stored in a locked cabinet. After the research study is completed, the tapes will be destroyed.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may also choose not to answer particular questions that are asked in the study. Your decision to withdraw will involve no penalty or loss of benefits to which you are otherwise entitled.

Your participation in this study may be stopped at any time by the study staff or the sponsor without your consent. The reasons might include:

- the study staff thinks it necessary for your health or safety;
- you have not followed study instructions;
- the sponsor has stopped the study; or
- administrative reasons require your withdrawal.
QUESTIONS

In the future, you may have questions about your participation in this study. If you have any questions, complaints, or concerns about the research, contact:

Sue Murdock, Ph.D.
Partnership for People with Disabilities
Virginia Commonwealth University
Phone: 804-827-1425
murdocksj@vcu.edu

If you have any questions about your rights as a participant in this study, you may contact:

Office for Research
Virginia Commonwealth University
800 East Leigh Street, Suite 113
P.O. Box 980568
Richmond, VA 23298
Telephone: 804-827-2157

You may also contact this number for general questions, concerns or complaints about the research. Please call this number if you cannot reach the research team or wish to talk to someone else. Additional information about participation in research studies can be found at http://www.research.vcu.edu/irb/volunteers.htm.

CONSENT

I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study. I will receive a copy of the consent form once I have agreed to participate. By signing this Informed Consent form, you give Virginia Commonwealth University permission to tape-record your responses during the focus group and you promise to keep all discussion and names of other focus group participants private.

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<tr>
<th>Participant name printed</th>
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Name of Person Conducting Informed Consent Discussion / Witness (Printed)

| _________________________ | ______________________| _____|
| _________________________ | ______________________| _____|

Signature of Person Conducting Informed Consent Discussion / Witness Date

| _________________________ | ______________________| _____|
| _________________________ | ______________________| _____|

Principal Investigator Signature (if different from above) Date
¿Vuéste un padre o miembro de la familia?
¿Tiene su hijo entre 1 y 21 años?
¿Son usted y su hijo hispanos?
¿Visita su hijo al doctor u otro especialista de salud por lo menos dos veces al año por motivo de su discapacidad o condición de salud?
¿Ha visto su hijo un doctor por lo menos una vez en los últimos seis meses?
¿Puede usted participar en una conversación de grupo por una hora y media?

Si usted puede, favor de contactar a Bernice Allen, R.N., Ph.D., al teléfono 804-827-1547 o envíe un correo a ballen@vcu.edu. Los grupos de enfoque se van a reunir en la primavera del 2010 en el norte de Virginia, Richmond, y Tidewater. Los participantes recibirán $100. Toda información es estrictamente confidencial.

Para saber más sobre este estudio de investigación y para inscribirse, favor de dejar un mensaje con su nombre y número de teléfono al siguiente número: 804-827-1547 o mande un correo a ballen@vcu.edu.

Alguién se pondrá en contacto con usted dentro de 48 horas.

Patrocinado por Virginia Commonwealth University – Partnership for People with Disabilities and the Virginia Department of Health (Asociación para Personas con Discapacidades y el Departamento de Salud de Virginia).
YOUR OPINION COUNTS!

We are looking for African American and Latino parents (or other family members) of children who have special health care needs to participate in a focus group. We are interested in your experiences and opinions about health care for your child.

★ Does your child have a developmental delay, health condition, disability or other health problem?
★ Are you a parent or other family member?
★ Is your child 1–21 years old?
★ Are you and your child African American or Latino?
★ Does your child see a doctor or other medical professional at least twice a year for the health condition or disability?
★ Has your child seen a doctor at least once in the last six months?
★ Can you participate in a group discussion for about 1½ hours?

If yes, please contact Bernice Allen, R.N., Ph.D. at 804-827-1547 or ballen@vcu.edu. Focus groups will be held in the spring of 2010 in the Northern Virginia, Richmond, and Tidewater areas. Focus groups will be in Spanish or English. Participants will receive $100. All information is kept strictly confidential.

To learn more about this research study and register, please leave a message with your name and phone number at 804-827-1547 or email ballen@vcu.edu.

Someone will contact you within 48 hours.

Sponsored by Virginia Commonwealth University -- Partnership for People with Disabilities and the Virginia Department of Health.