Latino Narratives of Disability in North Carolina:

Listening to and Learning from Latino Parents of Children with Special Health Care Needs

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Introduction

In North Carolina, like much of the United States, the proportion of the population that is Latino is growing. In the last 18 years, Latinos have gone from representing a small proportion of the population (1 in 100) to a much larger (7 in 100) and steadily increasing proportion. The change in North Carolina mirrors changes in the United States more broadly, with the proportion of the population that is Latino in the United States now above 15%. Estimates of the number of Latinos in the United States with disabilities vary considerably. Using the 2003 American Community Survey (ACS), the Center for Personal Assistance Services reported that the percentage of Latinos with disabilities was much lower (10.4%) than had been indicated by the 2000 United States census (20.9%). There is reason, however, to suspect that these figures may underestimate the extent of disability among Latinos as many new immigrants avoid contact with government institutions.

The growing number of Latinos in the United States has many consequences, among them that the diversity of cultural perspectives related to issues of health and wellness, and our particular topic, disability, is increasing. It now more critical than ever for professionals to understand and appreciate the implications of cultural variation in values, goals, and behavior as they relate to issues of health.

There is currently a lack of research on Hispanics' attitudes and beliefs about disability (e.g., Salas-Provance, Erickson, & Reed, 2002). To date most studies of the views of different racial and ethnic groups on disability have tended to focus on quantitative approaches, to the extent that they have been considered at all. A complementary approach to understanding the perspective of individuals toward disability is a narrative approach. A narrative approach emphasizes the stories that individuals tell about disability (or any other issue) and in doing so provides a rich understanding of the ways in which individuals view disability. Few studies of the narratives of parents of children with disabilities have been done, but where they have been done they have tended to reveal complex narratives associated with disabilities, narratives that are hidden in standard quantitative studies (Ferguson and Ferguson 1995).

Approaches that emphasize the narrative can catch important aspects of people's views missed by quantitative approaches. In particular, quantitative approaches are poor at addressing what Skinner et al. (1999) call the "deeper concerns with meaning and purpose". Those concerns include how parents make sense of what has and is happening to their child, what the child's disability means for the parent's life, and what the disability means in some larger context. These are the sorts of questions that parents of children with disabilities grapple with and that inform how such parents and families interact with the medical system; yet such questions have been poorly addressed by researchers, particularly for minority populations such as Latinos.

Here we use the narrative approach to consider the meaning and significance that Latino mothers of children with special health care needs attach to disability. We focus on

Latino mothers in North Carolina, with the idea that views of disability may differ with race, ethnicity and culture in ways that are important to the medical and public health communities. To complement the mothers' perspectives and to gain a fuller understanding of how disability is understood among Latinos in general, we also conducted focus groups with Latinos who did not have children with special health care needs. Questions guiding this research were:

- How do Latinos talk about, think about and understand disability?
- In what way are understandings of disability informed by culture?
- How do people create meaning surrounding disability?
- How and with what expectations do parents of children with special health care needs access services for their children? What barriers to health service access and utilization do Latinos face?
- What are the practical implications of Latino beliefs surrounding disability for service providers?

Recruitment

Because of our desire to learn about the experiences of families who may have differing levels of integration into formal support systems, and perhaps differing understanding of disability and ideas about appropriate and acceptable care for children with special health care needs, families were recruited to participate in a number of ways. Agencies and organizations dedicated to working with children with special health care needs, particularly those who serve large numbers of Latino families, were instrumental in recruiting families. Latino community groups that may come into contact with families who have children with special health care needs and churches serving large numbers of Latino parishioners were also effective at recruiting families for participation. Invitational flyers were posted at Latino stores and restaurants; several participants learned about the study in this way. Snowball sampling, or simply asking families we interviewed if they knew of any other families who might like to participate in this study was a highly effective way of reaching families.

We also wanted to understand the perceptions of disability among Latinos who did not have children with special health care needs, as these might differ significantly from the perspective of families with children with special health care needs. To this end, we organized two focus groups with Latino lay health advisors (El Pueblo).

Methods

We used a mixed method approach that was qualitative in design. Twenty-two families with children with special health care needs were interviewed using a semi-structured interview guide developed by the researcher in conjunction with the Advisory Board at the Division of Public Health, Women's Health Branch (See Appendix A). Interviewees

were queried on four topic areas: 1) cultural construction of disability, 2) health care access and utilization, 3) barriers, and 4) experiences with the health care system in North Carolina.

Questions were open-ended and we allowed and encouraged participants to speak to us about the things that were most important to them in conveying their experiences with the children with special heath care needs. With the exception of one interview where the participants were most comfortable speaking English, all interviews were conducted in Spanish and took place in the participants' homes. Interviews lasted an average of two hours. With the exception of three families who chose not to have their conversation with us recorded, interviews were recorded. In addition to the semi-structured interview, participants also completed a demographic survey (See Appendix B). All interviewees signed an informed consent statement (see Appendix C). All families who participated received a $25 Wal-Mart gift card and gift for their child valued at approximately $25.

In addition to the individual interviews, we conducted two focus groups with Latinos (both men and women) who did not have children with special health care needs. Focus groups were conducted using a focus group guide, which contained questions similar to those posed to the mothers, but were not specific to parents of children with special health care needs (See Appendix D). As with mothers, topics covered included cultural construction of disability, health care access and utilization, barriers and experiences with the health care system in North Carolina. Focus group participants received $20 gift cards and a meal was provided at each site.

Demographic Profile of Participants

We conducted interviews with 22 Latino families with children with special health care needs living in North Carolina. Geographically, our sample was largely comprised of families living in and around the Triangle area of North Carolina. Eighty-five percent of the families we interviewed lived in Wake, Durham, Orange, and Johnston counties. With the exception of one interview where both the mother and father were present, we spoke only with the mothers, and the mothers completed the demographic survey. One mother declined to complete the demographic survey.

Most of the women in the study were born in Mexico and had migrated to the U.S. more than six years ago, where their children had been born (Table 1). The average woman in the study had been in the United States 7.6 years (+/- 4.4), had 2 (+/- 0.5) children. Roughly half (11/21) of women had household incomes of $29,000 or less, though two women reported household incomes more than $45,000. The average woman had a middle school, or more rarely, high school education. Only four women had completed high school and only one had attended college. Most women regarded themselves as reading Spanish good or very good, with only two women claiming to read very little. Most women however (and despite an average time in country of more than six years) reported that they were unable to read English (5 women reported "none," 14 women

reported “very little.” The results were nearly identical for spoken English. Our sample is largely characterized by low socioeconomic indicators.

Table 1. Country of origin for mothers in the study, their time in the U.S., country of birth for their children and the number of children they have, on average by country of their birth.

	Country of Mother’s Birth	Time in U.S.	Country of Child’s Birth	No. of children
US	0	NA	15	2.2
Mexico	16	6.8	4	2
Other Latin American	5	10.4	2	2.5

The majority of children, (14 of 21), saw just one doctor, and all but two women reported having a regular doctor for their child. Half (11 of 21) of the women had visited their child’s doctor in the last 30 days, but seven had not visited a doctor within the last three months. Only two of 21 women had insurance, but children were almost all (17/21) insured by Medicaid, with the remaining children either having no insurance (2) or private insurance (2).

A wide range of special health care needs was captured in our sample. Six children had autism or an autism spectrum disorder (Asperger’s), three had attention deficit disorder (ADD) or attention deficit hyperactive disorder (ADHD), three had learning disabilities, two had hydrocephalus, one had Type I Diabetes, one had asthma, two had hearing problems, one had partial blindness, one had epilepsy, one had cerebral palsy and one had a “shoulder and neck problem.” We did not press participants for a clinical diagnosis.

Results

Analyses of the interviews and focus groups revealed several major themes, or narrative components, that people frequently drew upon when talking about people (or their children) with special health care needs.

Language of “Disability”

We attempted to make few assumptions about how our participants thought about, talked about or understood “disability.” Moreover, we did not want our own language or way of speaking about “disability” or “special health care needs” to overly influence how the mothers responded to us. To these ends, our interview guide was designed to elicit the language mothers themselves used to speak about their children, and moreover, to draw out their own stories and experiences. We allowed mothers to tell their own stories or narratives, in their own language, and with their own words. We were interested in finding out: What words do mothers use to speak about their children and their children’s special health care needs? What words are acceptable/unacceptable or

appropriate/inappropriate? Do different types of people (mothers with children with special health care needs and people without children with special health care needs) use a similar language of disability?

During our interviews and focus groups, a large number of words were used to describe people with special health care needs or certain conditions of disability. Words ranged from clinical or medical descriptions (autistico/autistic, Síndrome de Down/Down's Syndrome, Spina Bifida/Spina Bifida, retraso de aprendizaje/learning disability) to pejoratives (loco/crazy, tonto/dumb, dañado/damaged, retardado/retarded). It should be noted that none of our participants said that they used the pejorative terms or believed them to be acceptable, but rather they referenced these as words that "other people" use to describe people with disabilities. Medical terms were considered by most participants to be acceptable/appropriate terms, and a number of value-neutral words were used by many participants and deemed acceptable/appropriate (discapacidad/disability, disabilidad/disability, necesidad especial/special needs, retraso/delayed). Another set of terms we frequently heard from participants fall under the category of terms of endearment and while not negative value judgments were not considered appropriate or acceptable, especially by mothers of children with special health care needs, who it should be noted, did not use these terms (problemitas/little problems, simple/simple, pobrecito/roughly poor baby, inocente/innocent).

- Discapacidad
- Disabilidad
- Con problemas
- Problemitas
- Simple
- Dañado
- Enfermo
- Pobrecito
- Retraso
- Retardado
- Retraso de Aprendizaje
- Necesidad especial
- Autístico
- Tonto
- Inocente
- Loco/Loquito
- No se compone
- Síndrome de Down
- Spina Bifida
- Ciego
- Mudo
- Lento
- Débil
- Especial

Key Themes in Narratives

Beyond the task of eliciting the language of disability, we sought to understand how Latinos construct disability and create meaning surrounding disability. Understandings of disability are culturally constructed. Through listening to the narratives that mothers of children with special health care needs used to frame their experiences, we were able to identify many central themes or narrative components that reveal insight into understandings of disability. More directed questions were presented to focus group participants. It is important and significant to note that not all themes were mentioned by every mother, but there were many shared among them; and not all themes mentioned by

focus group participants were shared by mothers (and visa versa). As will be discussed later, the differences between focus group participants, or those individuals who did not have children with special health care needs, and mothers of children with special health care needs were great.

- Pity
- Isolation
- Fear
- Disability as Punishment
- Shame
- The Good Mother
- Disability as Test
- Acknowledging Disability
- Resistance to Labeling
- Familial Responsibility
- Disability and Disease
- Advocacy and Partnership
- Stress
- Barriers to Service Access and Use
- Medical Home and Service Use

Pity

I feel sorry when I see a child in a wheelchair – he can't run and play or do things like other children. (Focus group participant)

Expressions of pity were frequently mentioned by focus group participants. Feeling sorry for people, especially children, with special health care needs was expressed as an acceptable reaction to a person with a disability. While expressions of pity were often followed up by attempts to focus on positive attributes that the person might have ("a beautiful smile," "a loving nature") or things that the person might be able to do ("sing with the voice of an angel"), having a disability was viewed as a challenge for both the individual and the family.

Pity is a theme that has been noted in various studies of Latinos and disability. Previous research suggests that pity is not a negative value judgment but rather a "compassionate expression" for those with disabilities, particularly in the socioeconomic context where physical labor is often necessary for economic stability (Graf et al, 2007).

No mothers, however, expressed pity for their own child, and when we did hear them express sentiments of pity, it tended be about how they felt in the past, before having their child. They did recognize that other Latinos, and other people in general, may feel pity for children with special health care needs.

Isolation

I know a family [in Mexico] who always kept their son in the house. He had problems with his legs and he couldn't walk, and when he got too big to carry around, he just sat in the house all day. (Mother of a child with special health care needs)

Almost all people that we spoke with, including focus groups participants and the mothers of children with special health care needs, knew of or had heard a person with a special health care need who was in some degree isolated, usually within the home; almost all of these stories took place in their native countries, usually in rural areas. While nearly everyone had stories of isolation to share, it is important to note that no one thought that this was an acceptable way to treat people with disabilities.

Like expressions of pity, isolation is a theme common in the body of literature on Latinos and disability. Graf et al. (2007) sheds some light on the topic of isolation by suggesting that where it does occur, it is not necessarily due to feelings of deep shame or embarrassment. Rather, in the socioeconomic context where families do not have enough money to purchase wheelchairs or leg braces, where mobility aids are frequently makeshift, and public buildings and transportation services are often not handicap accessible, isolation can and does occur.

No mothers that we spoke with considered themselves to have isolated their children, but many had stories of isolation of other people with disabilities that they shared.

Fear

I remember not wanting to be near this boy who had problems. I was afraid of him – and I don't know why – he was just different and I had never seen anyone like him before. I remember I wouldn't get on the elevator with him, I was so afraid. (Mother of a child with special health care needs)

In his study, Graf et al. (2007) suggested that one effect of isolating those with disabilities in Latino communities is that their lack of integration breeds fear among those who are not disabled. It is important to note that neither the focus groups participants nor the mothers of children with special health care needs expressed any current fear of people with disabilities. Some noted that children might fear a person who "looks different and acts different," but this type of fear was considered juvenile and inappropriate, yet "innocent" and a mistake of children.

Punishment

You hear about a family that has a child with a problem, but you're not supposed to talk about it, you never see them out in public, and you just know that that mama feels bad, like she did something wrong to have a child like that. (Mother of a child with special health care needs – talking about how she felt before she had a child with special health care needs)

Previous research in the area of Latinos and disability has called attention to how Latinos use religion to explain and make sense of disability. Likewise, in our conversations with

mothers, and to a much lesser extent during our focus groups, participants used explanations that were largely religious in nature to explain certain aspects of disability or responses to disability. In the above quote, a mother draws on the idea of disability as punishment (from God) for some past transgression, and the accompanying response of shame and guilt. It should be noted that although the concept of religious punishment associated with disability is often mentioned by researchers (Maestas et al, 2002, Mardiros et al, 1986, Graf et al, 2007), it was, in fact, rare among the people with whom we spoke.

Shame

If you can't have a perfect child, it's like you have not been able to do the one thing most important for a woman. Women feel ashamed (verguenza) for this. Not shame for the child, but for yourself. (Focus group participant)

Women, including mothers of children with special health care needs and mothers in our focus groups, spoke frequently of the strong relationship between womanhood and motherhood. Their comments centered on the accepted cultural notion (recognized as such by Latinos) that women's identities are inherently connected to their role as mothers. Women largely viewed children as a reflection of their parents, and children's behaviors, skills, social graces, strengths and weaknesses were perceived as deriving from the care of their mothers. In this context, having a child with a disability can be a shameful event. Most participants expressed very "mainstream" comprehension of the possible causes of disabilities (biology, chromosomes, chemical exposure, accidents, lack of oxygen during birth…), yet these understandings of the possible causes of disability did not entirely erase the deep shame people perceived that mothers of children with special health care needs felt. Yet, as further evidence of the differences between how mothers of disabled children are perceived by broader society and how those mothers see themselves, no mothers of children with special health care needs expressed any feelings of shame.

The Good Mother

I am his mother, he is my son. This cooking and cleaning and diaper changing and feeding, driving from here to there and talking to this therapist and that therapist is not my job – it is simply who I am as his mother.

During the interviews, almost every mother that we spoke with discussed their roles as mothers of children with special health care needs. Every mother attempted to convey that they were fulfilling the requirements of this unique role in the best way that they possibly could. Being a good mother implied strength of character, sacrifice for the well-being of the child, service and devotion, unconditional love, and daily care. While women often spoke of the many roles they played – as woman, wife, daughter, and sometimes even professional, the role of mother was often elevated above others.

Disability as Test

I do not think He would send me a child like this if He did not think I could handle it. I think that He expects more of me.

Like the idea of disability as a punishment from God, the idea of disability as a test (from God) was not frequently heard or implied by mothers of children with special health care needs (and never by focus group participants). Yet it was a strong part of the narratives of two mothers. These women spoke about the disabilities of their children as God's test of their worthiness and strength. Rather than as "punishment" noted above, these women believed that they were selected to have their children because of their strength and courage. Both said that God "does not give you things he knows you cannot handle." In accepting this test, women viewed themselves as becoming better people in the process of raising their children. Even mothers who did not speak explicitly about being tested often noted that having a child with a special health care needs caused/forced them to become better people – more accepting and tolerant, giving and gracious. Such explanations have been found in previous research (Skinner et al, 1999), though were perhaps less prevalent here than previously reported.

Acknowledging Disability

Finally, my mother-in-law, who raised a son herself who was discapacitado, said to me, something is not right. And it was like I saw my child with new eyes, and nothing was ever the same. (Mother of a child with special health care needs)

Finding out he had autism was a real shock. I cried and cried –still sometimes. But then I realized that knowing this does not change who he is – he is still the same little boy. Once you get over the initial shock, you can start to get on with life. It is life. (Mother of a child with special health care needs)

During the interviews, we asked mothers about how they first learned about their child's special health care needs. For many mothers, this was a very overwhelming and traumatic event, be it at the birth of their child, when they began to notice that their child was not reaching the same developmental milestones as other children, or when they found out from a doctor that "something was not right." Studies have found that Latino children with special health care needs are often "diagnosed" later than white children as well as children of other minority groups (Newacheck et al, 2004, Garcia et al, 2007). While structural barriers have been used to account for the delay, other research has pointed to the role of Latino cultural norms and values as possible contributing factors. Some research has suggested that Latino parents accept a broader range of "normal" behaviors in their children, and are less concerned about the inability of their children to reach certain developmental milestones. As our research was not comparative, we were not able to assess for these types of differences. Interestingly, however, when we asked participants about differences they perceived between the way Latinos and white Americans think about disability and people with disabilities, they did identify these very issues.

Americans are always reading the books and wondering, oh, is my baby rolling over and eating solid food. We Latinos are more easy going about it and just let the babies be babies, not that we don't love them and spend every minute with them…maybe sometimes it gets us…sometimes we just are not looking for the right clues to know that something is a little different. (Mother of child with special needs)

In this case, the participant identifies lack of knowledge about developmental milestones and a broader range of "normal" as factors that might delay seeking a clinical diagnosis. In no cases did we hear stories of mothers who "rejected" the idea that their child had or might have special health care needs. We did not hear stories about women who "pretended not to see," as one focus group participant suggested might be the case, developmental delays or behavioral issue, etc., in their children. Instead, we heard stories such as one mother's visit from doctor to doctor in an attempt to find out why her child was not able to sit up, or about how another "went to school as often as [her son]" to try to figure out why he was not able to keep up with the other children in class. The stories that mothers shared with us quite often centered on their search for understanding, quite often from a medical perspective, about their children's conditions.

Resistance to Labeling

He has been labeled since he was born. He's delayed or a little slow to develop. Now, everywhere we turn people want to diagnose him. Or they want to know what his diagnosis is. (Mother of a child with special health care needs)

My son is a child. He likes to draw and watch his cartoons. I don't like to say he is autistic. He is not a brand name. When I need to, I do, but otherwise, he is just a kid. (Mother of a child with special health care needs)

While the mothers we spoke with frequently sought out doctors and specialists in an attempt to get a diagnosis (and possibly a "cure" or treatment), and most expressed some relief at "finally knowing," the "labels" or clinical terms that professionals use to describe their children is often not what they want to hear "everywhere [they] go, from everybody, even the cashier at Wal-Mart." As we designed the interviews to try to elicit the terms and words that mothers used to describe their children, we were surprised often by how far we could get into the conversation before we learned their child's "diagnosis." This was not because mothers do not know it, or because they were uncomfortable using medical terms or because they translated strangely into Spanish. Rather, these terms were often simply not instrumental for them in speaking about their children. Mothers could, as the one illustrates in the quote, use the medical terms when they "need to," often when interacting with professionals. An interesting exception to this resistance to using medical terms was often found when speaking with mothers who attended an autism support group.

Somewhat related to the resistance we found mothers had toward labeling their children is the finding that mothers frequently downplayed their children's limitations or

challenges. For example, even when a broader range of "normal" behavior is accepted, as it may have been, having a five-year-old who is not able to feed herself or is still wearing diapers might be considered reasonable challenges. We found mothers far more open to talking about the special strengths of their children rather than their challenges. One possible explanation is that the mothers all too frequently had to talk about their children's challenges, and we were also asking about their strengths and successes. Another possibility, however, is that mother's frequently and systematically downplay their children's challenges, and this might have significant implications for health professionals working with Latino families.

Family Responsibility

A widely described value among Latinos is the family. The Latino family is frequently noted as a source of great support in much of the literature. Family members are those that you turn to in times of need. Associated with this ideal is the idea that problems are to be dealt with within the family, and that bringing in "outsiders," including professionals, can be considered unacceptable. From both groups of participants, we heard that it is primarily the family, particularly the mother and father, who should assume care and responsibility for the health and well-being of people with disabilities, both children and adults. In a slight contrast with the ideal of "keeping things within the family" however, mothers that we spoke with were actively engaging professionals in the care of their children and actively seeking professional advice on how to assist their children. Children in our sample were receiving medical care (59% had been to the doctor's office in the last 6 months), therapists were visiting them in their homes, children were attending developmental day centers and mothers (and some fathers) were attending support group meetings. Even stronger evidence for the acceptability of "outside" support was found in one mother's own words:

We want help, we want to know about the latest kinds of therapies for our kids, and about what we can be doing to help them at home. I know sometimes they [professionals] *think, that woman will not understand what I am trying to say. But I'll try. Sometimes I think they think we are too uneducated to do what is right for our kids.*

Far from the negative "isolating" effect of *familismo* that is often perceived, we found a much more positive use of familial responsibility among the mothers with whom we spoke. Family, particularly the mother, was viewed as the primary caretaker, and the entire family was perceived as having some responsibility in matters of care and support, yet the expertise of professionals was highly valued. We found a very strong willingness and desire to engage professionals in the care of children with special health care needs.

Disability and Disease

My child is not sick. He probably goes to the doctor less than lots of other children. This is who he is as a person. Nothing can "fix" him. Nothing needs to be fixed.

Mothers acknowledged that their children had a special health care need, but largely did not regard them as ill or diseased. Exceptions to this are mothers of children who had "special needs" such as diabetes, cancer, asthma. Such "illnesses" were considered as such, and families sought or hoped for medical "treatments" and "cures."

Advocacy and Partnership

You have to always be on top of things. You can't just stop and rest when you've found something, you have to be always involved, and of course, I want to be.

I know there's help, I look and look, and get a little, but I know there must be more for my son out there.

People say I am a stay at home mom. Well, this is a real job I have – not just taking care of my son but making sure others do to.

If I don't do it, who else will?

Central to many mothers' stories was the role of advocacy on behalf of their children. While many perceived that there was a definite lack of services, they also recognized that there were some that were available to them, and that they had to actively search for them, and pursue all possible leads. Mothers felt that it was their "job" to do this for their children. Being a good advocate included doing things such as searching for community resources for children with special health care needs, learning about their children's special health care needs and sharing this information with others so they understand the challenges their children face, meeting with teachers and school administration, making sure that therapists and other professionals "do their jobs," protecting their children against the "stares, laughs and abuses" of other children and adults and attempting to educate others about their children's needs, and "lots and lots of searching, for everything and anything that can help." Beyond simply finding services, mothers perceived their roles as advocates as requiring a kind of partnership with professionals. Several mothers mentioned that they wanted to be able to help therapists come up with a plan for their children "because I know what will work for him and what will motivate him." Many mothers stressed their roles as advocates for their children and attempted to covey to us that they were doing all that they could to ensure that their children were being well taken care of. Being a strong advocate for their children was implicitly tied up with being a good mother.

Provided all of the barriers that Latinos face in accessing and utilizing services which were mentioned by participants (learning about services, language barriers, fear, financial hardship, transportation, childcare, and relocation), advocacy is no easy job. While mothers expressed a strong need to advocate, and some reported being quite effective with stories of triumph ("I called and called, and talked with this and this and this person, and finally, they said, oh sure, we have a place for him this year"), quite often, the stories mothers told entailed not being entirely successful, or at the very least, being left, after all of their effort, feeling like they did not accomplish what they set out to do. Shapiro et al.

describes this as “alienated advocacy” and suggests that while “collaborative partnership between parents and professionals is a cornerstone of the special education and service systems, this relationship exists more as an ideal, especially when low-income, culturally diverse families are involved” (2005).Despite their advocacy, many mothers expressed that they often felt that they were not effective at locating services, and that they felt left out of important decisions related to their children’s care.

Immigration

I have a brother-in-law with a disability…there was no help for him…I remember thinking, I will not let not let the same thing happen to my son that happened to him. Better we came here [to the U.S.], even with all the problems, where at least we can get a little help for [him].

When he was little, there were lots of programs and help for him. It was so good for him, and they all loved him. No one ever said, “where is he from” – well, they did, but it did not really matter. Well, now it does matter. And I have to look and look for something for him. And there’s nothing! He is still a child, how can they do this to a child?

If you need directions, you use a map and look it up. It’s the same for us, but there is nowhere to look.

During the course of the interviews, we heard many stories of families struggling to get help for their children. Among the most difficult stories, however, were those we heard from families who came to the United States in search of a better life, and better services for their children. Only two families with whom we spoke fit into this category. At the time of the interviews, the children involved were teenagers, both of them with special health care needs that required extensive and long-term medical care, and were no longer eligible for Medicaid because of their documentation status. The stories these mothers shared with us are revealing in a number of ways. Mothers were compelled to immigrate with their children because they felt they would not be able to afford the type of care and services their children required in their countries of origin, even if they were available. They also perceived care to be better here.

Stress

Studies of stress and depression among Latina mothers of children with special health care needs are present in the literature. Largely, studies have found an increased risk of stress and depression among Latina mothers. While we did not set out to learn specifically about stress, it frequently arose, both directly, “I get so stressed sometimes, I lie in my bed at night awake and my head just spins” and indirectly, “there is not enough time in my day to get everything done that I need to. Families of *niños especiales* should get *tiempo especial* (special time), extra time.” While mothers’ narratives were largely positive, most women also reported feeling stressed, at times overwhelmed, and sometimes exhausted by their responsibilities. Previous work indicates that informal family support is a critical coping resource, and an expectation, in many Latino families,

even if dire socioeconomic circumstances makes support difficult to realize (McCallion et al 1997, Magana 1999). New immigrants in North Carolina, however, are often without any family or close friends, so this informal support that is consistently found to be so helpful is quite often missing. Anecdotally, when we asked mothers if there was anyone in their family who could help them if they needed it, many responded that they did not have any in the state.

Medical Home and Other Service Utilization

Research indicated that among children with special health care needs, minorities are more likely than white children to be without health insurance coverage, to be without a usual source of care, and to report inability to get needed medical care. Access and utilization disparities remain between white and minority children with special health care needs, with Latino children experiencing especially disparate care (Newachek et al, 2005). Despite the barriers mentioned above, and contrary to what we might expect given the previous research on care and coverage of Latino children with special health care needs, our demographic survey indicates that 90% of the children in our study had a usual source of care; 81% reported having Medicaid, 9.5% private insurance and 9.5% had no insurance.

The mothers in our sample reported being highly satisfied with the health care services their children receive. Most reported having a good relationship with their child's primary health care provider, and they believed that the provider interacted well with their child, took the time to answer the mothers' questions, and responded to their concerns.

Many mothers reported that it was through their children's primary doctor (be it a specialist, family physician) or office support staff that they first learned about other resources that might be available for their children. The role of these providers in connecting families to the resources that their children need should not be underestimated.

All of the children with special health care needs included in our sample were receiving (or received, if they were older at the time of the interview) some type of early intervention services. Most reported being very satisfied with the support they were receiving.

Barriers to Service Access and Utilization

While mothers reported being generally satisfied with the services their children were receiving, when we questioned them about specific barriers that might prevent them, or other families from receiving needed care and services, several were mentioned. Focus group participants suggested a similar set of barriers. These are:

- Learning about Services
- Language Barriers
- Fear (immigration status)
- Financial Struggle
- Transportation, Childcare, Relocation

Learning about Services

Learning about and gaining access to needed services can be challenging for any parent; for parents who are not members of the majority culture, these tasks can be especially daunting. In addition to the usual challenges inherent in learning about something with which one has little experience or knowledge ("I did not even know what the word autism meant"), Latinas experience difficulties due to a host of other barriers. Those include language barriers, lack of familiarity with cultural expectations for appropriate help-seeking behavior (I didn't really know that I had to call and call if I wanted anyone to call me back."), fear because of their immigration status or their child's immigration status and associated self/family protective desire to "not stick your neck out too far." Mothers reported that learning about services required a good deal of effort and interaction. As did figuring out if their children were eligible for them. Mothers reported that their primary care physicians were instrumental in referring them to other services. Mothers also reported that learning about services is an ongoing process. Many mothers reported that they are continually trying to figure out "what else might be out there." While most mothers reported being very satisfied with the services they were receiving, at the same time they lamented the lack of more services.

Language Barriers

Ninety percent of our sample can be characterized as "linguistically isolated." Most reported that they could speak or read English "very little" or "not at all." Language presented a major challenge to families when attempting to learn about their children's disability, learn about services and eligibility, and in attempting to access services. Mothers reported that very little information was available about their children's disability in Spanish, and this presented a problem very early on in trying to learn about what they might expect.

When I found out that he had autism, I thought, autism, what is that? I wanted to learn everything I could, because I thought that maybe the more I knew, the more I could help him, maybe get better. Well, can you believe that it was so hard to find anything in Spanish, you might think that people who speak Spanish do not get autism …

The majority of the mothers we spoke with reported using interpreters in their children's doctors' offices, and reported that they were satisfied with these interpreters, but that they would prefer Spanish speaking physicians and nurses. Mothers reported that "home visitors" (therapists, social workers) were less reliably bilingual. This presented uncomfortable situations where there was someone in their home working with their children, whom they could not communicate with well. One mother reported that her child received speech therapy in English, a language the child does not regularly speak, nor understand. Linked with the clear barrier that language presented is the finding that mothers were not always sure what agencies they were involved with, or how they were linked, if at all. Language problems often seemed to result in confusion:

There was a woman, a therapist, coming here and working with [son]. One week, she didn't show up. Then another woman, a gringa, came to the house, but I'm not sure if she is from the same group or what. I tried calling, but the interpreter was not in, I'm not sure who this therapist is now, or if she'll stay.

Fear

I will ignore all of the fear that I feel when I have to give some office my name and address because I know that most people are good and this is for my child. You see, this is all that we have. But people get picked up at Burger King…so you have to be careful.

Many Latinos think that wherever they go, people are watching them and wondering if they are illegal, not just poor people, but Latinos from all classes. I think this extends to medical areas. The fewer people you interact with, the less likely you are to get deported.

After he could no longer get Medicaid, then I was very afraid, thinking, where could we go, what would I do if he got sick, how are people going to react?

Financial Struggle

Slightly more than 50% of the families we interviewed reported a household income of $29,000 or less. Daily financial struggle is a reality for these families. We found most often that the majority of family resources (including time, money, and effort) was spent addressing the needs of their children with special health care needs.

When we have a little bit extra, we can always think of something that [our daughter] could use. Soon we will have to get a new van, and we have to start thinking about how we can do it. I save whenever I can, because I know that we have to always be prepared.

Mothers were very grateful for the assistance their children received free of charge such as early intervention programs, assistance they received in special education schools or programs, developmental day centers and Medicaid. Many also reported, however, that "all the other expenses [associated with caring for their children] add up to more than we make, and add on top of that just getting through the day. It is hard."

Transportation, Childcare, Relocation

Families reported a variety of other challenges affecting access and utilization of health care services. Lack of transportation to and from appointments, childcare for other children during appointments and therapy sessions, and the difficulties families faced if they relocated such as transferring records, finding new services and providers and establishing relationships with providers were frequently cited by mothers and focus group participants.

Key Findings

1) Latinos share a common set of cultural values, beliefs and perceptions surrounding disability.

AND

2) Understandings and perceptions of disability are shaped by culture and experience.

We set out to understand the perceptions of Latinos surrounding disability, particularly as they related to the care of children with special health care needs. To these ends, we conducted interviews with families with children with special health care needs and complemented those interviews through focus groups with Latinos without children with special health care needs. A significant finding of this research is that there were large differences between these two groups of participants, and while some cultural values, beliefs and norms were shared (and most certainly commonly understood and recognized), the mothers of children with special health care needs largely shared a set of values and perceptions that was unique to them. For example, all participants understood pity, shame and punishment to be commonly held ideas surrounding disability among "Latinos," yet mothers of children with special health care needs understood these sentiments in very different ways – usually as ignorant and biased responses. Conversely, the mothers frequently expressed far more positive responses to people with disabilities and shared in an entirely different set of values that pertained to being a mother of a child with special health care needs. The experience of having a child with special health care needs largely shaped the mothers' responses to disability (in general) and certainly to the challenges their children faced. Here then the culture associated with mothers of children of disabilities was more relevant than the culture associated with being Latino.

3) Structural, rather than "cultural" barriers to service access and utilization were the most frequently noted among participants.

While all of the families we spoke with were receiving services such as early intervention therapy, school-based special education programs, and or developmental day center programs, the difficulty that mothers reported in gaining access to these and other services was quite salient. Elsewhere, we have detailed these barriers (language, knowledge of services, financial hardship, transportation, childcare…). While certain

commonly held cultural notions might influence when and whether or not families seek assistance (such as issues associated with acknowledging a disability in the first place or consistently "down-playing" their child's challenges as we mentioned previously), for the most part, the challenges families faced in gaining access to services were largely structural in nature. In other words, mothers' beliefs or attitudes about disability did not, for the most part, inhibit them from seeking services. Rather, everyday things like not having a car to get to an appointment, or not being able to pay for a needed intervention or not being able to understand the instructions given about where to go and with whom to talk were the major problems mothers faced.

4) Mothers expressed a desire for formal social support for themselves and their families.

An inadvertent benefit to having a quorum of children with autism or autism spectrum disorder in our sample was the ability to assess, indirectly, the effect of a formally organized support group for families of children with autism. Unlike other mothers in our sample, most of the mothers with children with autism attended a regular support group meeting. This meeting is moderated in Spanish by a Latina, who also has a child with autism. The mothers who attend this group appeared to have fewer problems associated with knowledge of services than other mothers, and while they frequently encountered challenges in accessing service, like almost all other mothers, they were extremely active and effective "advocates" for their children. The support group, one mother said, "gave me the power to feel like I can do this, and it gave me the skills and the emotional support to really be able to…" Women frequently mentioned the support group as the primary source of information about autism. The support group provided both the emotional and instrumental support (in the form of information and resources) most mothers desired, but outside of the support group members, few encountered. Mothers of children with special health care needs other than autism also reported attending the group and cited it as a rich source of information and support.

This image of the effective and valued support group, however, contrasts sharply with a generally held notion that, as one focus group participant stated it, support groups are "things that Americans [sic] do." The sentiment expressed by this participant, suggests that Latinos do not value and would not attend support groups. We found quite the opposite when speaking with mothers.

Limitations of the Research

As with any study, there are several limitations to this research. Future research might address these to further our understanding of Latinos and disability.

Small Sample Size

We spoke with 22 families. While we did see clear patterns of responses and themes, and our findings are largely in keeping with results from previous studies of Latinos and

disability, increasing the sample size may yield additional themes. We might consider, for example, how effective we were at attempting to include families who were not well integrated into health care services/community services in the state. We did not speak with any families, for example, who were not involved in a program for children with special health care needs. The theme of isolation (of people with disabilities) that emerged repeatedly might leave us to consider the extent to which this might occur in our own state, and whether or not there is a significant number of children with special health care needs who are not in any way being served by our state's formal support systems.

Geographic Specificity

The majority of the families we spoke with lived in largely urban areas of the state. Large portions of our state, however, are primarily rural or semi-rural, and we might consider that health care service access, utilization, and general satisfaction with services available might vary considerably depending on where one lives.

Perspective

We spoke primarily with mothers. We are left to wonder whether or not fathers share a similar set of knowledge, attitudes and beliefs about disability, and more specifically, about their children's disabilities. While we were available to meet with families at any time that was convenient for them, including evening hours to accommodate working fathers/partners, it was the mothers who contacted us, arranged the interviews and with whom we spoke. What particular narratives might fathers construct? What other narrative components might emerge from discussions with fathers? Future research might specifically target or include fathers for further investigation.

Recommendations

The qualitative methods used in this research were particularly effective at eliciting mothers' stories and revealing cultural norms and values that were not "imposed" by the research methods. Often, we (social science researchers), and medical professionals among others, assume we know enough about the people with whom we are working to formulate our framing questions, our clinical prescriptions, our behavioral suggestions. In other words, we assume we know what makes people tick and what we should say or do in order to elicit certain responses. If anything, this research has shown that every mother has a story that she uses to make sense of her child's disability and to frame her present and plan for the future. We also found that many (cultural) values, norms and beliefs revealed in these stories are shared among Latinos, and to an even greater extent, among Latina mothers of children with special health care needs. It becomes the job of public health and medical professionals to understand precisely which stories are being told by the mothers of their clients. Understanding the information contained in these stories is central to connecting with Latina mothers of children with special health care needs. The following are some practical recommendations (informed by Skinner et al, 1999) for learning how to connect in meaningful ways with Latinos:

1) Do not assume that all parents, not even all Latino parents, share a similar understanding of disability. Parents often hold understandings of disability that are informed by culture, as well as by experience. The views of mothers of children with special health care needs differed in many ways from those of our focus group participants. This finding should warn against the tendency to homogenize "Latinos" (or African Americans, Native Americans …).

2) Listen to parents. What story is being told? Do they view disability as a punishment? Are they ashamed? Negative value judgments or sentiments such as these that may be associated with disability can have significant consequences for service seeking.

3) Recognize that mothers' narratives are malleable and ever changing. Intriguing in this research are the differences between Latinos with and without children with special health care needs. In some way, negative perceptions of disability such as pity, shame and punishment were transformed into more positive perceptions by the mothers with children with special health care needs. Certainly, having and loving a child was a factor, but we might also consider the influence of other messages they were receiving from family, friends and professionals.

4) Offer resources to help construct positive narratives. Professionals play a role in parent's stories and in the meanings that parents construct. A therapist who took the time to explain how a mother could work with her own child, a doctor who gathered Spanish language information for a mother whose son was recently diagnosed and other similarly sympathetic characters influenced how mothers thought about their children's challenges. The influence of an autism support group for Latino parents in shaping mothers' views of autism was very apparent. Mothers involved in this group expressed a kind of empowerment that was unique and probably not entirely explained by individual characteristics of the mothers.

Strategies for Improving the Inclusion of Latino Families with Children with Special Health Care Needs in Formal Support Systems

Provided the transformative effect that simply being included in "the loop" of information, resources, and support can have on families, the following are practical strategies gleaned from our research for improving the inclusion of Latino families with children with special health care needs into the formal support structures in North Carolina:

1) Alleviate the barrier that language presents for many Latinos.
- Hire bilingual/bicultural staff.
- Adapt written materials into Spanish.
- Hire professional interpreters.
- Ensure that the supply meets the demand.

2) Increase the capacity of community resources to work with Latinos.
- Provide cultural competency training and support.

3) Prepare Latinos for leadership roles in community resources.
- Recruit, train and utilize talented individuals.

4) Create a network of community resource communication and referral.
- Identify community resources engaged with Latinos.
- Ensure network visibility and up-to-date information.
- Get the word out (in Spanish) about where to go/who to talk to if you have a child with special health care needs or suspect your child might have a special health care need.

5) Refer families to community resources.
- Train staff at community resources to respond and to refer.

6) Make program information widely accessible for the Latino community.
- Use straightforward language, creative design and distribution.
- Encourage agencies to develop plans about how to work together to identify families and provide information about services and support.

7) Conduct Latino-specific program assessments of key community resources.
- Assess how well specific programs are serving their Latino clients.
- Identify good models.
- Identify and respond to areas of concern.

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Appendices

Appendix A. Interview Guide English

Construct of Disability

1. Tell me about your child. Tell me about the wonderful things your child can do and about the things that your child struggles with.

How do you prefer to speak about the special health care needs that your child has? What words or labels do you (or your child) like/not like to use?

What are the special health care needs your child has? What impact do they have on his/her daily life?

2. How did you first learn that your child might be different from other children (use preferred term from above)? What did you do to prepare yourself and your family to welcome and care for your child?

What sources of information or support did you access [Probe for family/community support AND for health/educational support]? What was most useful to you? Who or what did you trust?

3 How, if at all, have your ideas about disability (use preferred term from above) changed in the time that you have been a parent to (child's name).

4. In what ways, if any, has loving and caring for [your child] affected you and the other members of your family?

Probe: Financial strain, allocation of resources, time...

Medical Home and Care Coordination
5. Where do you usually take your child to when he/she is sick or you need advice about his/her health and how did you choose this provider?

Probe: What is important to you in a medical home?

6. How would you describe your relationship with your child's health care provider?

Probe: Does your child's health care provider respect you and your family – your values, culture and experiences? Are you able to communicate openly with him/her? Does he/she take the time to answer all of your questions? Does he/she "know" your child?

If hindered by language…

7. How do you communicate with your child's health care provider? Does he/she speak Spanish, or are interpreters available? Please tell me how this works when you have an appointment.

8.Who, or what other sources of information, advice or assistance do you turn to in order to help your child? Who do you trust/not trust?

Probe for community involvement, special programs, church programs…?

Barriers

9. People often delay or do not get needed health care. By health care I mean medical care as well as other kinds of care like dental care, mental health services, physical, occupational, or speech therapies, and special education services. What are the reasons why people may delay or not get needed health care? Have you ever delayed or gone without health care for your child? Please tell me about this experience

Probe for difficulty operating within healthcare system, language, culture, immigration status, financial concerns, time, distance, insurance problems, transportation, trust, convenience, racism, etc…?

10. In what ways, if any, does being Latino/a affect your experiences with the health care system in North Carolina [Probe for language, racism, cultural difference, immigration status, immigrant experience]?

Experiences with Health Care System

11. In your experience, how does the health care system in North Carolina differ from that in your country of origin?

Probe: Tell me about a positive/negative experience you have had with the health care system in NC.

12. In general, how would you describe your experiences with the health care system?

13. What could improve your satisfaction with the care your child receives?

14 . Is there anything else that you would like to tell us about your child or your family?

THANK YOU!!!

Appendix B. Interview Guide Spanish

GUIA PARA LA ENTREVISTA

1. Háble me acerca de su hijo/a. Dígame las actividades maravillosas que su hijo/a puede hacer y las actividades con las que el/ella tiene(n) problema.

(¿Como usted prefiere hablar de las necesidades especiales de salud que su hijo/a tiene? Que palabras o nombres le gusta a usted (o a su hijo/a usar) y cuales no les gusta?)

(¿Cuales son las necesidades especiales de salud que su hijo/a tiene? Que impacto tienen estas en la vida diaria de el/ella?)

2. ¿Como se enteró usted la primera vez que su hijo/ja sería talvez diferente entre otros niños (use el término preferido mencionado antes)?¿ Que hizo para prepararse a si misma y a su familia para la bienvenida y el cuidado de su niño/a?

¿A que medios de información u apoyo tuvieron acceso. [Trate de saber si hubo apoyo de la familia o comunidad y si hubo apoyo médico y educacional]. ¿Que es lo que mas le sirvió? ¿Que o a quien le tuvo mas confianza?

3. ¿Como, si en algo, han cambiado sus ideas acerca de discapacidades (use el termino preferido mencionado antes) en este tiempo que ha sido el padre de este niño/a (use el nombre del niño/a).

4. ¿De que manera, si alguna, el amor y el cuidado hacia (el nombre de el/la niño/a) le ha afectado a usted y a otros miembros de su familia?

Hogar Médico y Coordinación de Cuidados
5. ¿Hay un lugar al que usted lleva a (use el nombre del el niño/a) cuando el/ella esta enfermo/a o cuando necesita consultar acerca de su salud? Que clase de lugar es este? Es una oficina de doctor, el cuarto de emergencia, clínicas del hospital, una clínica u algún otro lugar?

6. ¿Como se comunica usted con el proveedor de salud de su hijo/a? El/ella habla español o tiene intérpretes disponible?.

7. ¿Como usted catalogaría la relación entre su hijo/a y su proveedor médico? Usted siente como que el doctor de su hijo/a lo escucha cuando tiene preguntas? ¿Y esta listo para contestar a sus preguntas en una manera fácil de entender? Se preocupa genuinamente acerca de la salud y bienestar de su hijo/a? Respeta a usted y a su familia?.

8. ¿A quien o a que otros medios de información , consejería o asistencia usted acude para ayudar a su hijo/a a alcanzar sus sueños y metas [Averigue si esta envuelto/a en programas de la comunidad, programas especiales, programas de la iglesia….]? ¿En quien usted confía y en quien no?

Barreras
9. La gente muchas veces se demora o no obtiene el cuidado médico que necesita. Al hablar de cuidado médico, yo me refiero a otros también como cuidados dentales, cuidados de salud mental, medicina general, ocupacional, o terapias del habla y también a servicios especiales de educación. ¿Usted alguna vez se ha demorado o no ha conseguido cuidado médico para su hijo/a? Por favor cuénteme acerca de esta experiencia [Averigue si hubo alguna dificultad trabajando con el sistema médico en los Estados Unidos, el lenguaje, cultura, estatus de inmigración, problemas financieros, tiempo, distancia, problemas de seguro, transporte, confianza, conveniencia, racismo, etc]?

10. ¿De que manera, si alguna, ser latino le afecta con sus experiencias en el sistema se salud de Carolina del Norte [Averigüe si por lenguaje, racismo, diferencias culturales, estatus de inmigración, experiencia de inmigrante]?

Experiencias con el Sistema de Salud

11. ¿En su experiencia, como el sistema de salud aquí en Carolina del Norte difiere de el sistema de salud en su país de origen?

12. ¿En general, como usted catalogaría sus experiencias con en sistema de salud de Carolina del Norte? [Averigue: ¿Cuales son los algunos de los aspectos positivos de sus experiencias con el sistema de salud de aquí? ¿Cuales son algunos de los aspectos negativos con el sistema de salud de aquí?]

13. ¿Que podría mejorar su satisfacción con el cuidado que su hijo/a recibe?

14. ¿Hay algo mas que a usted le gustaría decirnos o contarnos acerca de su hijo/a o su familia?.

GRACIAS!!!

Appendix C. Demographic Surveys

Survey & Demographic Information

1. What is your postal zip code?
   _____

2. Where were YOU born?
   Country: _____

3. If you were born somewhere other than the U.S., how long have you lived in the U.S.?
   - ❑ Less than 1 year
   - ❑ # Years _____

4. How many children do you have?
   _____

5. Where was YOUR CHILD with special health care needs born?
   Country: _____

6. How old is your child with special health care needs?
   Age:_____

7. What kind of health insurance or medical coverage does your child with special health care needs have?
   - ❑ Private insurance
   - ❑ Medicaid/ Health Check/Health Choice
   - ❑ He/she does not have health insurance or medical coverage
   - ❑ Other (If other, describe) _____

8. What kind of health insurance or medical coverage do your other children have? (Only answer if you have other children)
   - ❑ Private insurance
   - ❑ Medicaid/ Health Check/Health Choice
   - ❑ They do not have health insurance or medical coverage
   - ❑ Other (If other, describe) _____

9. What kind of health insurance or medical coverage do YOU have?
   - ❑ Private insurance
   - ❑ Medicaid/ Health Check/Health Choice
   - ❑ No health insurance or medical coverage
   - ❑ Other (If other, describe) _____

10. When was the last time your child visited a doctor or health care professional?
    - ❑ Past 30 days
    - ❑ Past 90 days
    - ❑ Past 6 months
    - ❑ Past 12 months
    - ❑ Past 2 years
    - ❑ Longer ago than the past 2 years

11. Does your child have a doctor or nurse that he/she usually visits?
    - ❑ Yes
    - ❑ No

12. Does your child regularly visit more than one doctor?
    - ❑ Yes
    - ❑ No

13. Which of the following best describes your ability to SPEAK in English:
    - ❑ Not at all
    - ❑ Very little
    - ❑ OK
    - ❑ Good
    - ❑ Very good

14. Which of the following best describes your ability to READ in English:
    - ❑ Not at all
    - ❑ Very little
    - ❑ OK
    - ❑ Good
    - ❑ Very good

15. Which of the following best describes your ability to READ in Spanish:
    - ❑ Not at all
    - ❑ Very little
    - ❑ OK
    - ❑ Good
    - ❑ Very good

16. What is your highest level of education?
    - ❑ No formal education
    - ❑ Elementary school
    - ❑ Middle school
    - ❑ Some high school
    - ❑ High school diploma or GED
    - ❑ Some university
    - ❑ University diploma

17. What is your annual **household** income?
    - ❑ Less than $15,000
    - ❑ $15,000-$29,000
    - ❑ $30,000-45,000
    - ❑ $45,000-$60,000
    - ❑ Over $60,000

Encuesta e Información Demográfica

1. ¿Cual es su código posta?
   _____

2. ¿En donde nació?
   País: _____

3. Si usted nació en cualquier otro país, ¿Cuanto tiempo ha vivido en los Estados Unidos?
   - ❑ Menos de 1 año
   - ❑ # de Años _____

4. ¿Donde nació su hijo/a con necesidades de salud especial?
   País: _____

5. ¿Cuantos hijos tiene?
   _____

6. ¿Cuantos años tiene(n) su(s) hijo/a(s) con necesidades de salud especial?
   _____

7. ¿Que clase de seguro o cobertura médica tiene su hijo/a que requiere de cuidado médico especial?
   - ❑ Seguro Privado
   - ❑ Medicaid/ Health Check/Health Choice
   - ❑ El/Ella no tiene seguro o cobertura médica
   - ❑ Otro si otro, descríbalo) _____

8. ¿Que clase de seguro o cobertura médica tienen su otros hijos? (Conteste solamente si tiene otros hijos)
   - ❑ Seguro Privado
   - ❑ Medicaid/ Health Check/Health Choice
   - ❑ El/Ella no tiene seguro o cobertura médica
   - ❑ Otro si otro, descríbalo) _____

9. ¿Que clase de seguro o cobertura médica tiene usted?
   - ❑ Seguro Privado
   - ❑ Medicaid/ Health Check/Health Choice
   - ❑ El/Ella no tiene seguro o cobertura médica
   - ❑ Otro si otro, descríbalo) _____

10. ¿Cual fue la última vez que su hijo visitó al doctor o a un profesional de la salud?
    - ❑ Hace menos de 30 días
    - ❑ Entre 31 y 90 días
    - ❑ Hace más de 6 meses, menos de un año
    - ❑ Hace más de 12 meses
    - ❑ Hace más de 2 años
    - ❑ Mucho más de hace 2 años

11. ¿Tienen sus hijos un doctor o una enfermera que el/ella visitan regularmente?
    - ❑ Si
    - ❑ No

12. ¿Su hijo/ja visita regularmente a más de un doctor?
    - ❑ Si
    - ❑ No

13. ¿Cual de los siguientes describe mejor su habilidad de HABLAR en Inglés:
    - ❑ Completamente nada
    - ❑ Muy poquito
    - ❑ Más o menos
    - ❑ Bien
    - ❑ Muy bien

14. ¿Cual de los siguientes describe mejor su habilidad de LEER en Inglés:
    - ❑ Completamente nada
    - ❑ Muy poquito
    - ❑ Más o menos
    - ❑ Bien
    - ❑ Muy Bien

15. ¿Cual de los siguientes describe mejor su habilidad de LEER en Español:
    - ❑ Completamente nada
    - ❑ Muy poquito
    - ❑ Más o menos
    - ❑ Bien
    - ❑ Muy Bien

16. ¿Cual es su nivel más alto de educación?
    - ❑ Ninguna educación formal
    - ❑ Educación Primaria
    - ❑ Algo de educación Secundaria
    - ❑ Secundaria completa
    - ❑ Algo de educación Universitaria
    - ❑ Diploma/Título Universitario

17. ¿Cual es el ingreso anual de su casa?
    - ❑ Menos de $15,000
    - ❑ $15,000-$29,000
    - ❑ $30,000-45,000
    - ❑ $45,000-$60,000
    - ❑ Más de $60,000

Facilitators: _____ Date: _____

Location/Site: _____

Appendix D. Informed Consent Documents

What is the purpose of this interview?

The purpose of this interview is to learn about how Latino families with children with special health care needs access and coordinate the health care services they need for their children. We are also trying to understand what Latino families think and know about disability and special health care needs. This information will be used by the North Carolina Healthy Start Foundation and the Women and Children's Division of the State Department of Public Health to improve their public education campaigns and outreach activities.

Why have you been asked to take part?

You have been asked to be in this study because you are the parent or legal guardian of a child with special health care needs.

What will you be asked to do?

You are being asked to participate in one interview that will take about 1 hour of your time. We will ask you about your experiences in accessing the health care services your child needs and about your ideas and perceptions about disability in general. Your ideas and opinions are important to us, so please just say what's on your mind. There are no right or wrong answers to any of the questions we are asking.

What are the benefits of participating?

We do not promise you any direct benefit from participating. The interview, however, may allow you to explore your feelings and beliefs about disability and special health care needs. Other people may benefit in the future because the information from this interview may increase our understanding of the best ways to talk to people about disability and allow us to improve outreach and education.

Are there any risks?

No. There are no known risks from participating in the interview. Are there any costs? No. There is no cost to participate. Will you receive any compensation? Yes. You will receive a $25 gift card to thank you for participating.

Right to Refuse or Withdraw

Participation in this interview is voluntary. You have the right to withdraw your consent or stop participating at any time without penalty.

Confidentiality:

If you agree to participate in this interview, please understand that your participation is voluntary. All the information you provide will be kept confidential. The only exception is if you express the intent to harm yourself or others. This signed consent form and your name will be kept separate from the interview information. You do not need to tell us your name and you may use a fake name if you wish. Audio-taping is preferred for all interviews, however, you may ask to stop the tape recording at anytime. All tapes will be transcribed (typed up) without names or other identifying information to protect your confidentiality. Every effort will be taken to protect the identity of the participants in the focus group. However, there is no guarantee that the information cannot be obtained by legal process or court order. You will not be identified in any report or publication of this focus group or its results.

Who can I contact to answer questions about the interview?

If you have questions about this interview, you may call Monica Sanchez, Coordinator, at 919-782-5187 or Ms. Janice Freedman, Executive Director of the North Carolina Healthy Start Foundation at 919-828-1819.

Participant's Agreement

I have read the information provided above and voluntarily agree to participate in this interview. I understand that I will be given a copy of this consent form.

_____ _____

Participant Signature Date

Información del Consentimiento para la Entrevista

¿Cuál es el propósito de esta entrevista?
El propósito de esta entrevista es aprender sobre como las familias Latinas que tienen niños con necesidades de salud especiales reciben y coordinan los servicios de salud que sus niños requieren. También estamos tratando de entender lo que las familias Latinas piensan y saben acerca de discapacidades y las necesidades especiales en la salud. Esta información será utilizada por la North Carolina Healthy Start Foundation (Fundación de Comienzos Saludables de Carolina del Norte)) y la Women and Children's Division of the State Department of Public Health (División de Mujeres y Niños del Departamento de Salud Pública del Estado). Esta información será utilizada por la North Carolina Healthy Start Foundation para mejorar sus campañas de educación pública y acceso a la comunidad.

¿Por qué le hemos pedido participar?
Le hemos pedido participar en esta entrevista porque usted es padre o tiene la custodia legal de un niño con necesidades de salud especiales.

¿Qué le pediremos hacer?
Le estamos pidiendo participar en una plática que tomará como 1 hora de su tiempo. Le preguntaremos acerca de sus experiencias con el acceso a servicios de cuidados de salud que su niño necesita y acerca de sus ideas y percepciones de discapacidades en general. Sus ideas y opiniones son importantes para nosotros, por favor diga simplemente lo que piensa. No hay respuestas correctas o incorrectas a ninguna de las preguntas que vamos a hacerle.

¿Cuáles son los beneficios de participar?
No le prometemos ningún beneficio directo por participar. Sin embargo, el grupo de enfoque puede permitir que usted exprese sus sentimientos y creencias acerca de discapacidades y necesidades especiales del cuidado de la salud. Otras personas podrían beneficiarse en el futuro, porque la información de este grupo de enfoque puede ayudarnos a comprender y encontrar mejores maneras para hablar con la gente sobre discapacidades y nos permitirá mejorar el acceso y educación de la comunidad**.**

¿Existe algún riesgo?
No. No existen riesgos por participar en el grupo de enfoque.

¿Tiene algún costo?
No. No tiene ningún costo participar.

¿Usted recibirá remuneración?
Sí. Usted recibirá una tarjeta de regalo de $25 en agradecimiento por su participación.

Derecho a rechazar o retirarse del Grupo de Enfoque

La participación en este grupo de enfoque es voluntaria. Usted tiene el derecho de retirarse o terminar su participación en cualquier momento sin ninguna represalia.

Confidencialidad:
Si usted esta de acuerdo con participar en este grupo de enfoque, entienda por favor que su participación es voluntaria. Toda la información que usted proporcione será considerada confidencial. Con excepción de que si usted expresa sentimientos de hacerse daño a usted mismo u a otros. Este documento de autorización firmado y su nombre se mantendrán separados de la información del grupo de enfoque. Usted no necesita decirnos su nombre, podría utilizar un nombre ficticio si lo quisiera. Todas las conversaciones de los grupos de enfoque son grabadas, sin embargo, usted puede pedir que se detenga la grabación en cualquier momento. Todas las cintas serán transcritas (mecanografiadas) sin los nombres o la información que la identifica para proteger su confidencialidad. Haremos todo nuestro esfuerzo para proteger la identidad de los participantes en el grupo de enfoque. Sin embargo, no hay garantía de que la información no pueda obtenerse a través de un proceso legal u orden judicial. Usted no estará identificada en ningún informe o publicación de este grupo de enfoque o sus resultados.

¿A quién puedo contactar para contestar preguntas sobre el grupo de enfoque?
Si usted tiene preguntas sobre este grupo de enfoque, usted puede llamar a Monica Sanchez, Coordinadora del programa, al 919-782-5187 o a Janice Freedman, Directora Ejecutiva de la North Carolina Healthy Start Foundation al 919-828-1819.

Acuerdo del Participante
He leído la información proporcionada arriba y acepto voluntariamente participar en este grupo de enfoque. Entiendo que me darán una copia de este Documento de Consentimiento.

_____ _____

Firma del Participante Fecha