


**A Program Model for Latino Family Support Services at  
the University of North Carolina Craniofacial Center**


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A Master's Paper submitted to the faculty of  
the University of North Carolina at Chapel Hill  
In partial fulfillment of the requirements for  
the degree of Master of Public Health in  
the Public Health Leadership Program.

Chapel Hill

2008

  
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## **Abstract**

Latino patients face many challenges when seeking health care because of sociocultural, financial, and language barriers, which influence the overall level of support for a family within and outside of the health care system.<sup>1,2,3</sup> At the University of North Carolina Craniofacial Center (UNC CFC), Latino families have identified a desire to connect with other Latino parents who have children with craniofacial differences and have also requested improvements in the Spanish craniofacial educational materials.<sup>4</sup> The provision of these supports, in theory, will augment the Latino's ability to successfully coordinate and cope with their child's care.

This paper designs a program plan and an evaluation plan for social and informational support services for the Latino patient families seen at the UNC CFC. The program includes the implementation of a bimonthly Spanish-speaking support group and the utilization of services through the Family Support Network of North Carolina to increase social support and subsequent volunteering of Latino families. To increase the informational support for the families, the program includes planned viewing times for a Spanish cleft lip and/or palate video as well as provision of Spanish craniofacial booklets manufactured by the Cleft Palate Foundation.

An initial assessment of the program will include a qualitative evaluation of the implementation of the program, and will include examination of records of service utilization and Latino parent focus groups. Future evaluations of longer-term outcomes will include pre- and post- intervention surveys of the Latino parents receiving the services, and informal interviews with UNC CFC staff members. If this project successfully creates a supportive social and educational environment for the parents and families of Latino patients, it can serve as a model for culturally appropriate support programs to be implemented within other fields in health care.

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## Introduction

Between the years 1990 and 2000, the Latino population in North Carolina has increased by 400% to become the fastest growing Latino population in the nation.<sup>5</sup> The increase in this population necessitates culturally appropriate adjustments of the distribution of public services, especially within the field of health care. Latino patients face many challenges when seeking health care because of sociocultural, financial, and language barriers, which not only affect health outcomes, but also influence the overall level of support for a family within and outside of the health care system.<sup>1,2,3</sup> Latino patients often feel socially isolated, marginalized from community institutions, and unprepared to handle the challenges of acquiring care in such a foreign environment.<sup>6</sup>

When a child is born with a cleft lip and/or palate or craniofacial difference, it is common for parents to feel overwhelmed, uninformed, and isolated in their attempts to identify the next steps necessary for their child's care.<sup>7</sup> Latino parents' acquisition of appropriate and timely cleft care is further hampered by the multitude of barriers that affect them logistically and socially.<sup>8,9</sup> If the mother did not receive a prenatal diagnosis, the initial shock comes to the family as they comprehend the reality of having a child with a craniofacial malformation. The family then must navigate through the health care referral system to locate a center that provides multidisciplinary craniofacial care; uninsured or impoverished families might not be knowledgeable about centers that are accessible for those with minimal financial resources. Transportation to a center such as the University of North Carolina Craniofacial Center (UNC CFC) may be difficult for families from distant counties in North Carolina, and family members must take time away from work and other responsibilities at home. Once at the clinic, the family encounters language, social,

and cultural barriers. When they return home, the social isolation that often accompanies these new parents intensifies by the many needs of their child. Parental access to adequate social support can buffer the stress of all of these challenges, especially when this social support is from parents experiencing similar challenges.<sup>10,11</sup>

Multidisciplinary clinics are often required for children or adults with craniofacial malformations, and they provide most craniofacial services in the United States.<sup>12,13</sup> A child with a cleft often undergoes many surgeries before the age of two, but the care provided in these clinics is much more comprehensive than just surgical consultations. Other services include speech therapy, otolaryngology, orthodontics, dentistry, audiology assessments, social worker visits, and psychology assessments.<sup>12</sup> The integration of the many disciplines fosters interdisciplinary collaboration and a shared rehabilitation goal for the child with the cleft.<sup>14</sup> Clinics are set up so that each patient and family goes from room to room to visit each specialty in one day. For a young family that speaks only Spanish, the clinic quickly becomes overwhelming because of the assessments, recommendations, timelines, and education provided by surgical and other teams.

Literature demonstrates the benefits of interdisciplinary centers that synthesize clinic visits; these clinics ultimately relieve the families who no longer have to make multiple appointments and trips to their specialty hospital.<sup>13,14</sup> However, with the recent growth of non-English speaking patient populations, these centers can become overwhelmed with the communication and culture barrier.<sup>9</sup> The patient families often leave with misunderstood information or little understanding at all, not only because of interpretation and translation errors, but also because of social and cultural differences that preclude the family from clarifying instructions.<sup>15</sup> During their visits, it is critical that all families receive and fully comprehend

relevant rehabilitation and support messages, understand their child's condition, become aware of the options for treatment, and find available financial assistance.<sup>16</sup> Proper education and a social support structure are necessary to improve the preparedness of families for the many years of care to come.

Because of cultural differences, Latino families have different beliefs and attitudes about their child's disability, which may amplify confusion.<sup>9,17,18</sup> The need for culturally appropriate staff and faculty in multidisciplinary clinics is for not only pertinent for Latino populations, but also for various Asian and African communities.<sup>8,19</sup> The lack of similarity between members of the craniofacial team and their Latino families, stemming from ethnic differences and from the fact that most team members do not have a child with a craniofacial malformation, prevents them from serving as support models.<sup>16</sup> Sophisticated, English-speaking parents are able to navigate the system, as well as the Internet, with a self-help mentality to find other similar families. In contrast, Latino parents often cannot find this niche of other parents or organizations to answer the logistical and social/emotional questions that arise when one has a child with a cleft, because this niche may not exist among Latino parents. Despite this, UNC CFC serves as the liaison between families by connecting the parents with other patient families to serve as the foundation of assistance and encouragement.

The University of North Carolina's Craniofacial Center (UNC CFC) attempted to identify the cultural, social, and communicative barriers existing for their growing Latino population through a survey in 2005-2006 of two thirds of their Latino patient families.<sup>4</sup> This survey illustrated the variety of beliefs of the etiology of craniofacial differences held by the Latino craniofacial parents, as well as the need for improved Latino support services. The Latino participants identified their desire to connect with other Latino families who have children with

craniofacial differences, requested improvements in the translated Spanish educational materials, and voiced difficulties with calling the center when no one is immediately available to speak in Spanish. Knowledge of social networks and appropriate cleft care will empower the families, encourage them to become actively involved caregivers, and ultimately benefit the Latino population with an improved understanding of the health care system.

### ***Goal of this Masters Paper***

In this paper, I will devise a program and an evaluation strategy for planned support services provided by the UNC CFC for their Latino patient families. This support program will ideally improve Latino craniofacial patient families' understanding of the clinic, of their child, and of available support systems. Other craniofacial teams have identified the need for culturally appropriate Latino care, however, there is little literature regarding the creation of sustainable support structures within a minority population such as the Latinos at craniofacial centers.<sup>15,9</sup> I will develop an approach that provides Latino support services beyond the craniofacial services provided to all patients within the clinic. Following this, I will identify an evaluation strategy for the future assessment of the efficacy of these services. The goal is that this program model to increase Latino support and preparedness is not limited to the field of craniofacial care; but that it may serve as a general model for the education and empowerment of Latinos within other health disciplines as well.

## **Background**

A broad overview of Latinos in the United States and in North Carolina is presented here to more completely understand the Latino population seen at UNC CFC. The structure and functioning of a craniofacial clinic are described to illustrate the complicated and comprehensive care required for a child with a craniofacial malformation. The many needs of the families needing craniofacial services magnify the lack of support that already exists for the Latino population. Finally, this section includes a literature search that identifies similar family support programs that have been previously evaluated.

### ***Latino Americans***

Persons of Hispanic origins, here referred to as Latino, have recently become the largest minority population in the United States.<sup>5</sup> This population includes people from Mexico, Puerto Rico, Cuba, Spain, and Central and South America. Within the country, the states with the largest Latino populations are California and Texas; other states with high Latino populations are New York, Florida, Illinois, Arizona, and New Jersey. These states all have populations of one million or more, and have had growing Latino populations for many years.

As mentioned earlier, North Carolina has a unique Latino population. The state has experienced the most rapid growth of Latinos over the past two decades when compared to all other states in the nation.<sup>20</sup> The Latinos in North Carolina represent a different subgroup of Latinos; two-thirds of Latinos within North Carolina are foreign-born, compared to 45.1% foreign-born nationally.<sup>21</sup> Almost all of these foreign-born Latinos are not naturalized citizens, whereas nationwide only ~70% of foreign-born Latinos are non-citizens. As many of the Latino



people in North Carolina are recently immigrated, it is comprehensible that 34% report speaking English poorly or not at all. Similar to the rest of the country, most of the Latinos living in North Carolina are from Mexico, with others from Puerto Rico and Cuba as well.<sup>21</sup>

**Culture** As a high proportion of the Latinos in North Carolina are recently immigrated, assimilation to the traditional American culture has not necessarily occurred. The Latino culture differs from American culture in many ways, and there is much diversity among different subgroups of Latinos as well. Similarities among most Latinos include the Spanish language and an emphasis on the role and relationships of the family.<sup>21</sup> Latinos recently immigrated have lower educational levels and job security compared to other Americans; many consider themselves religious with attachments with the Roman Catholic Church. Mexican and some Puerto Rican populations may have immigrated for economic reasons, while Cubans more often have immigrated for political reasons.<sup>21</sup>

**Family** The family exists as a central support system for most Latinos.<sup>21</sup> Latino women have the highest birth and fertility rates nationally, with 99.4 live births per 1,000 women ages 15-44 years, compared to 58.3 for white women and 67.2 for black women.<sup>22</sup> Both the high birth rate as well as the continual immigration contribute to a younger mean age among Latinos when compared to the rest of the United States, (24 versus 35 years old).<sup>21</sup> Initial immigration to North Carolina was largely male, (59.8% of NC Latinos are male); however, recent estimates show that entire families and single females are immigrating to the state at higher rates.<sup>21</sup>

**Employment** North Carolina Latinos have higher employment rates than persons of other population groups, but tend to work in occupations that are lower-paid and require manual labor, such as construction, production, and farming.<sup>21</sup> Latino migrant farmworkers who work seasonally are not included in these estimates, and may reach 60,000 in number in North

Carolina alone. Because of different occupational positions held, over one-quarter of North Carolina Latinos live in poverty.<sup>21</sup>

**Health** Health care utilization patterns among Latinos add to the cultural complexity of this population. Latino children are twice as likely as Caucasian children to be uninsured, and most with insurance have Medicaid.<sup>3,23</sup> Barriers to seeking health care include problems with transportation, excessive waiting times, a lack of linguistically appropriate services, and inconvenient clinic hours for working parents. A study conducted in Boston found that though Latino children often were up to date on immunizations and had regular physician checkups, 21% of families brought their children to emergency rooms for routine sick visits.<sup>23</sup> For children with disabilities, it is often the mother's responsibility to care for the child, and she thus makes many of the child's medical decisions.<sup>24</sup>

**Health Behaviors** Latino cultures value respect for authority figures, which may include physicians, nurses, and other health professionals.<sup>24</sup> They may show this respect in ways that differ from other American patients, such as by avoiding eye contact and not asking questions. Latino families will often avoid disagreements about treatment options while in the presence of authority figures in order to avoid disrespect. In return, the family expects respect and empathy from the physician for their illness. This respect implies personal decency, and it must be established between the provider and patient upon the initial meeting.<sup>25</sup> In addition to this, Latino families will expect their provider to function with *personalismo*, or warmth and friendliness combined with authority and professionalism.<sup>24</sup> Latinos are accustomed to physical contact, often in the form of sitting close to providers or vigorous hand shakes.<sup>25</sup> Patients may consider it a weakness if their physician suggests acquiring a secondary opinion for a medical condition, and may consider a provider cold and distant if they do not offer a handshake.

Another personal value among the Latino population, with no English equivalent term, is *simpatico*. This refers to a “personal quality of an individual who is likable, attractive, fun to be with, and easygoing”.<sup>24</sup> Latino patients value physicians’ ability to exhibit this attribute while also being able to provide excellent care.

**Health Beliefs** Health beliefs among recently immigrated Latinos may run counter to traditional Western biomedicine. Many Latinos believe in *curanderismo*, or folk healing, performed by a curandero.<sup>24</sup> *Curanderismo* is a type of medicine that utilizes herbs, religion, and psychosocial interventions to treat the patient with the help of the patient’s family. A Latino patient may seek the advice of a curandero before he or she will go to a Western physician, especially true of illnesses not manifested with outward signs of disease, such as cardiac disease. *Curanderismo* believes that multiple influences cause illness, most commonly natural and supernatural forces, imbalances of heat and cold, and emotions. Patients that believe in this kind of folk healing consider Western medicine to heal the symptoms of disease, and traditional Latino medicine to heal the underlying cause of disease.<sup>25</sup> Curanderos are part of the community in which the patient lives; they suggest treatments and provide counseling for the social and cultural disturbances that accompany all illnesses.

*Curanderismo* explains that the development of cleft lip and/or palate has a superstitious cause, namely maternal exposure to supernatural forces during a lunar eclipse.<sup>24</sup> A woman can try to prevent clefting once exposed to a lunar eclipse by wearing a belt with an attached key for the rest of her pregnancy. Though anthropologic literature regarding traditional belief systems such as *curanderismo* abounds, rarely will patients in a biomedical setting disclose that they seek this form of treatment. It is important to recognize that many Latino patients do not believe in *curanderismo*, and may rely solely on Christian religions such as Catholicism and Western

biomedicine for healing. Catholicism is the most common religion among North Carolina Latinos, and may attribute congenital anomalies to God's will. Belief in this can result in feelings of maternal guilt, irrespective of educational attempts to explain medical etiologies of clefting.

Knowledge and acceptance of these cultural variations is required of health care personnel, and explicitly among craniofacial providers according to the American Cleft Palate-Craniofacial Association (ACPA).<sup>26</sup> Even after adjusting for variables such as insurance status, income, and severity of disease, minority populations are less likely than Caucasian populations to receive adequate health care.<sup>27</sup> Health disparities are likely due to linguistic and cultural barriers and fragmentation of the system, as opposed to patients' attitudes towards health care or treatment preferences. Health outcomes reach their fullest potential when both providers and patients acknowledge their different perspectives but make the conscious decision to trust one another in collaboration for health.<sup>24</sup>

### ***Craniofacial Care – an Interdisciplinary Approach***

The treatment of cleft lip, first documented in China in the 4<sup>th</sup> century AC, involved cheiloplasty, or the sewing together of the edges of the lip.<sup>13</sup> Cleft palate surgical treatment was first documented in 1816 by Carl Ferdinand Graefe. Since the latter part of the 20<sup>th</sup> century, literature has recognized that interdisciplinary care delivers the maximum benefit for patients.<sup>28</sup> Teams of plastic surgeons, oral-maxillofacial surgeons, dentists, audiologists, speech pathologists, psychologists, and many others collaborate to provide individualized, comprehensive care in accordance with ACPA team standards.<sup>12</sup>

This approach is superior to singular approaches to care, as many children with cleft lip and/or palate have other associated disabilities, including hearing problems, speech difficulty, social problems, and possibly other craniofacial anomalies.<sup>28</sup> The distinction of teams as ‘interdisciplinary,’ as opposed to ‘multidisciplinary,’ implies that the different professionals conduct a joint evaluation and treatment plan for each child, as opposed to independent assessments. This cohesive assessment of the child promotes the best possible outcome from each discipline represented. The team functions to coordinate complex services and multifaceted evaluations as well as address the psychological and social needs of the families.<sup>28</sup>

The team approach to craniofacial care has matured the awareness of the need for social dimensions of care. These teams emphasize the need for family involvement in decision-making and treatment planning.<sup>28,15</sup> As awareness of the need for culturally appropriate support services increases, it becomes apparent that Latino families can help identify and plan services that support other families with similar challenges. Garwick et al. report that “actively including family caregivers from diverse cultural backgrounds in the planning, implementation, and evaluation of services and programs is one strategy that could increase the likelihood of meeting family needs.”<sup>15</sup> Strauss illustrates that “one of the most powerful components of the [craniofacial] system is the other families.”<sup>29</sup> He stresses the early development of allies among families; this gives parents another parent to call about logistical and emotional questions that can only be comprehended by another with the same everyday experiences.

### ***A Typical Craniofacial Team***

Shortly after the birth of a child with a craniofacial malformation, one of the providers of the team makes initial contact with the family. If diagnosis was made prenatally and the mother

delivers at UNC, this visit will often occur while the mother and child are still admitted to the hospital. At this point, a succinct conversation illustrates to the family the importance of seeking early care for the child, both to improve surgical outcomes as well as to ease the social and logistical complications of caring for a child with a craniofacial difference.

At the initial diagnostic clinic assessment, the families begin at the administrative office where they check in, take pictures of the child, and fill in requisite insurance forms. For families that do not have insurance, financial assistance is available within the UNC Health System with applications in the clinic. From administration, the patient and family go to clinic visits with plastic surgery, oromaxillofacial surgery, otolaryngology, orthodontics, dentistry, psychology, social work, and speech therapy. After the patient visit, the team conferences to decide a treatment plan with a rotating team leader from one of the above disciplines. A comprehensive treatment plan that summarizes the individual consultations during the day is then mailed to the patient family for their review.

At UNC CFC, various team members have recognized the surge in the Latino population and subsequently administered a survey to Latino families to acquire their demographic and sociocultural information. Of the participants in the survey, 88% were from Mexico, a higher percentage than the U.S. percentage of Latinos of Mexican origin. Most of the men worked in construction, agriculture, or as other laborers, and most of the women stayed at home.<sup>4</sup> Though 81% of families had moved to North Carolina in the past 10 years, most of the patients were born and diagnosed in the United States. Most Latino families cited that the UNC CFC serves as their primary support structure for the care of their child. This survey described the demographics, beliefs, and values of the growing number of Latino patients served by UNC CFC, and also provided the opportunity for feedback of existing services. Parent feedback established some of

the needs of the Latino community that were not addressed at the clinic or elsewhere, such as a desire to connect socially with other Spanish-speaking craniofacial families. The providers reinforced existing Latino patient protocols, but also recognized the need for further interventions to improve the overall approach to caring for this population. As a response to the survey, the team conducted a family-led focus group to further identify the needs of this population. As a result, a dedicated phone voicemail line at the CFC was established for Spanish calls, to be checked twice weekly by the Spanish interpreter.

### ***Programs to Increase Family Support***

To determine the feasibility of implementation and evaluation of this Latino support program, published literature describing similar family support interventions was reviewed. Using Pubmed, CINAHL, and Google Scholar, subjects with terms such as “parent to parent,” “Latino,” “disability,” “cleft,” “family support,” and “evaluation” were searched, as well as bibliographies of relevant articles to find original or related articles. All together, one randomized trial and several observational trials were identified. Most articles evaluated parent-to-parent support programs, while others described and evaluated comprehensive programs that included support groups and/or informational support (see Table 1 in Appendix for a list of measurement outcomes and tools from these studies).

This literature search resulted in much information regarding coping strategies of parents and families who have a child requiring extensive medical care. Parents respond differently to the pressures and stresses of having a child with a disability. Coping mechanisms vary among different ethnicities and socioeconomic groups, and may vary according to the disability of the child.<sup>30</sup> Available support systems include the extended family, neighbors, friends, and the

professionals who treat the child. Social and informational support provided by parents with similar challenging daily experiences can effectively augment the adaptation and coping processes for these families.<sup>31,32,33,7</sup> Comprehensive support for Latino families must also include culturally and linguistically appropriate support. This includes provision of resources regarding craniofacial anomalies, available social services, community programs, and financial information.<sup>34</sup>

**Parent-to-Parent Programs** One of the goal interventions for the UNC CFC Latino parent support program is the arrangement of parent-to-parent pairings, which most often comprises a ‘veteran’ parent and a ‘referral’ parent.<sup>11</sup> The parents participating in these pairings offer emotional, informational, and social support to another parent either in person or via telephone over an extended period of time. This pairing provides another individual who listens and understands, who models good coping strategies, and who shows hope for the future; these pairings lead to less alienation and increased emotional and problem-solving support among the parents.<sup>34</sup> A third party, the organizer of the network and often a social worker or parent of a disabled child, matches the referral parent to an appropriate veteran parent based on the disability of the child, the age of the child, the proximity of the families, or cultural backgrounds. Training of veteran parents in fully developed programs typically includes provision of information regarding listening and communication skills, adjustment to the diagnosis, available community resources, information about the specific disability, the influence of positivity, and the referral process.<sup>35</sup> Some program trainings include provision of relevant information about financial options, leadership, and cultural diversity. These programs are successful because of the perceived similarity between the two parents’ daily challenging experiences, allowing the transfer of encouragement, reassurance, and practical advice.<sup>31,10</sup>



One research team in this field of parent-to-parent support networks conducted a study looking at the effect of parent-to-parent organizations on parents' ability to cope, their sense of empowerment to acquire health and social services, and their acceptance their child's disability.<sup>32</sup> The authors utilized randomly assigned intervention and control groups as well as quantitative and qualitative measures with validated tests to evaluate these outcomes. This team found statistically significant improvements in parents' self-reports through participation in the parent-to-parent program, and 89% of participating parents found the program helpful. The parents that participated in the program reported better coping abilities, viewed their families in a more positive way, and aided other similar parents, but there was not a significant increase in parental sense of empowerment. From the qualitative interviews, parents that did not find the program helpful (11% of the participating parents) either did not have initial contact with their pair parent, or found the match inadequate. Though the parents included in this study were primarily middle and upper class and Caucasian, the authors believed that comparable programs for ethnic minorities would prove to be equally successful.<sup>32</sup>

Kerr and McIntosh evaluated parent-to-parent support programs for parents of children with upper limb anomalies qualitatively using retrospectively collected data and interviews with parents.<sup>7</sup> They found that parental contact with other similar parents provided additional coping abilities as well as emotional, social, and practical support.

Another parent-to-parent network used pre- and post-intervention structured interviews.<sup>36</sup> Outcomes the authors were interested in included depression, anxiety, anger, and cognitive disturbances among the parents. The study group that received the intervention did not differ significantly in these outcomes from the group that did not receive the intervention. The study cited various reasons why they may have not acquired the expected quantitative results, but they

did qualitatively determine that the program had beneficial effects for the parents in the intervention group in terms of depression and anxiety.

One study further evaluated the parent-to-parent support system qualitatively to determine the qualities that make a match successful.<sup>10</sup> Similar to other studies, they examined the summative outcomes of the participants, such as family empowerment, perceived social support, acceptance, and coping, but also did a formative evaluation of the success of program implementation. They found that successful matches depended on perceived likenesses between the parents, the bi-directional nature of support, availability of both parents, and situational comparisons. When the referral parent's child had a worse condition than the veteran parent's child, this was considered an "upward comparison" and made a match unsuccessful; the reverse situation made a match successful.

**Comprehensive Programs** Comprehensive programs have included a more intensive intervention than parent-to-parent pairings alone, often including support groups and provision of information relevant for parents of children with special needs. Several programs described below were conducted in intensive care units (ICUs), as these settings often involve very sick children and parents previously unaware of the needs and services their child will require.

One comprehensive parental support program for neonatal ICU parents consisted of parent pairings as well as an educational parent support group, and was evaluated quantitatively.<sup>37</sup> Veteran parents received 5 hours of training on issues such as communication and boundaries for offering support. The authors used a cohort design and evaluated parental stress, anxiety, depression, and perceived social support using standardized self-report measures. They found statistically less state anxiety, stress, depression, and greater perceived social support among participating parents, and 21 of 24 mothers found the program helpful.

The COPE program (Creating Opportunities for Parent Empowerment) was a randomized, controlled trial involving child and parental educational-behavioral interventions instituted in a pediatric ICU.<sup>38</sup> The intervention included distribution of written and audio information with a corresponding workbook, and intended to increase parental knowledge of normal child behaviors and parental involvement in their child's treatment. Outcomes measured included parent participation in the child's care, mood state, depression, maternal beliefs, stress, and maternal anxiety. The authors found improved maternal functional and emotional coping outcomes in the intervention group. Relevant measurement scales included the State Anxiety Inventory, Profile of Mood States, Depression Subscale, Involvement in Emotional Care, Index of Parent Participation, Parental Beliefs Scale, and self-report questionnaires. All COPE projects, six in total, from 1992 through 2006, utilized strong experimental designs and interventions. Five of the COPE trials were randomized controlled trials and one was quasi-experimental. While this program intervention is different from that planned for the Latino craniofacial families, it did include the provision of informative and practical education, as the Latino craniofacial program intends. Interventions varied greatly among the trials, but each was successful in contributing to the literature of parental coping techniques and strategies.<sup>39</sup>

Qualitative evaluation of a neonatal ICU parent education and support group program included questionnaires.<sup>40</sup> Through these questionnaires they found that the support group gave personal perspective, increased perceived support, aided in resource location, and improved the interactions between parents and their children.

One research team determined the effectiveness of a family intervention program through questionnaires of parents, evaluating individual, marital, parental, and extended family relationships.<sup>33</sup> The intervention involved nurse-provided familial support as well as an

informative booklet. There was no comparison group. The authors found that the program was beneficial for families by teaching them about their child's disability, by aiding their assimilation into the new world of the disability, and by providing written information.

**Applicability** Most families participating in parent-to-parent support networks are the parents of a child with a developmental delay, Down syndrome, mental retardation, or a learning disability, though many disabilities can be represented.<sup>35</sup> The majority of participants in these support systems are Caucasian mothers in a two-parent household with incomes above \$35,000. According to a national sample of parent-to-parent networks, only 3.5% of participating parents were Latino.<sup>32</sup>

The efficacy of parent-to-parent networks and support groups might differ for Latino families due to various reasons: "It should not be assumed that positive behavioral support interventions will succeed ...for families from diverse cultures."<sup>41</sup> Past support programs of this nature have been unsuccessful for Hispanic families, probably because of poor cultural fit and socioeconomic differences between participants.<sup>30</sup> Harry outlines six key realms of difficulty when designing culturally relevant support services.<sup>42</sup>

1. cultural differences in definitions and interpretations of disabilities;
2. cultural differences in family coping styles and responses to disability-related stress;
3. cultural differences in parental interaction styles, as well as expectations of participation and advocacy;
4. differential cultural group access to information and services;
5. negative professional attitudes to, and perceptions of, families' roles in the special education process; and
6. dissonance in the cultural fit of programs

Evidence of past failures of formally structured family support programs for Hispanic families indicates the programs' cultural inadequacies, and suggests the need for an evaluation of a culturally appropriate support program.<sup>30</sup>

Latino mothers seen at the clinic, which undoubtedly have varying degrees of acculturation and biculturalism, may differ in their perception of their child's disability. Latinos recently immigrated may have a broader spectrum of normalcy and may be more likely to participate in support programs than Latinos who are more acclimatized.<sup>42,43</sup> Latino families in general have greater resilience to familial stress than European American families.<sup>42</sup> Because persons with disabilities or craniofacial anomalies have traditionally been considered "minorities", disabled persons within ethnic minority groups have often been overlooked (and identified primarily as disabled) when doing family support research. Because of this, little is known of how culture influences family perceptions of disability, and there is need for future research of family support programs for ethnic minorities.

## **Program Plan**

### **Program Context**

#### ***Background***

The UNC CFC was created sixty years ago as various practitioners in the UNC Healthcare system recognized the need to provide multi- and inter-disciplinary care for children and adults with cleft lip and/or palate and other craniofacial differences. These practitioners appreciated the importance of assessing and improving the psychosocial functioning of the patients and their families in addition to treating the orofacial cleft and resultant speech impediments. The clinic now functions twice weekly in the UNC School of Dentistry, in Chapel Hill, North Carolina. The staff and providers see over 2000 patients on an annual basis. Twenty

years ago, the clinic rarely treated Latino, Spanish-only speaking patients, but since the late 1990s the numbers of Latino patients have grown to become about one in every five patients.<sup>44</sup>

**Mission** – The mission of the UNC CFC is “to provide optimal care for patients with cleft lip, cleft palate and other craniofacial anomalies through an interdisciplinary team-oriented approach and to stimulate biological, behavioral and clinical research that will ultimately lead to an improved quality of life for our patients.”<sup>45</sup>

**Latino Craniofacial Program Overview** – The first section below describes the current clinic layout and activities with descriptions of providers’ roles and responsibilities. The second section describes planned future elements of the support program for Latino families, parts of which include activities external to the UNC clinic itself.

### **Existing Clinic Description**

- **Team Members**

The team is composed of specialists from 13 fields: adult general dentistry, plastic surgery, oral and maxillofacial surgery, orthodontics, speech-language pathology, speech pressure-flow assessments, social work, psychology, pediatric dentistry, otolaryngology, feeding and swallowing, pediatric neurosurgery, and pediatric ophthalmology. Referrals to other fields, including audiology and pediatric genetics, occur on an as-needed basis. In addition to these providers, the staff includes 1 patient care coordinator, 3 administrative assistants, and 1 Spanish interpreter dedicated to the clinic’s Latino patients for each one of their visits.<sup>46</sup>

- **Team Responsibilities**

The team members’ responsibilities include clinical examinations and assessments of the patients. Latino patients are scheduled extended visits one day each week because of the need for interpretation. The providers are

encouraged to meet with the Spanish interpreter prior to visitation with the parents to clarify diagnostic goals and preferences. Providers are instructed to speak in short phrases for ease of interpretation, to speak directly to the patient and or the family (not to the interpreter), and to be aware that the interpreter may interrupt for clarification. Each of the providers may have a variation of their regular assessment for the evaluation of Latino children. For example, speech therapists must be aware of and knowledgeable of pronunciation and intonation differences between Spanish and English. After the clinic day, the team congregates to discuss each patient separately and determine his or her treatment plan. This plan is translated into Spanish as a recommendation list by an outside translator service, and mailed to the families.<sup>46, 4</sup>

- Spanish Medical Interpreter

The interpreter has a bulk of the responsibilities to ease the assimilation of the Latino family into the CFC environment. Before the patient's scheduled appointment, she calls the family to remind them of the appointment and help with financial documentation. She meets the family upon arrival, and reinforces the importance of confidentiality to gain the families' trust. At the administrative office, she aids the family in filling out insurance and privacy forms. She makes the patients and families aware of the financial aid available through the clinic and through the UNC Hospitals. She then leads the patients and families from specialist to specialist throughout the School of Dentistry and faithfully interprets all questions to and from the patient. Between appointments, the interpreter continues to interact with the patient and family. It is at this time that many families clarify previous instructions or ask further questions. The interpreter makes certain that the families continue to be comfortable at the clinic. She serves as an advocate for the family and answers questions not addressed in the office. The UNC CFC also has a Spanish-accessible phone line. When Spanish-speaking patients call the clinic, they can receive a Spanish voicemail service. The interpreter dedicated to the clinic

checks messages twice weekly and returns all calls after clarifying the need or question asked by the patient.

- Patients and families

Often patient families visit the plastic reconstructive surgeon prior to their initial diagnostic clinic appointment; at other times, their child has already undergone an initial operation. The patients and their families (when the patient is a child) schedule a diagnostic clinic visit upon the initiation of the team care. Families arrive at the clinic by 8 am on their appointment day, where they proceed with the interpreter to the administrative office and other appointments. Clinic appointments run from arrival until about 12:30 pm.

- Activities

Before a Latino family's first diagnostic clinic visit, they receive in the mail an information packet containing Spanish versions of a welcome letter, the privacy policy, and a booklet describing the functions of the clinic and staff.

Administrative paperwork in English is also in the packet, to include a patient information form, lodging information, consent forms, insurance forms, and directions.

### **Planned Support Program (\*see Implementation section for further detail)**

Anticipated additional services for Latino patients will include activities that will either:

- 1) enhance the availability of culturally relevant, easily accessible, and understandable informative craniofacial materials (informational support), or
- 2) provide a supportive environment in which the Latino families can foster personal and community qualities of mutual support, advocacy, and volunteerism (social/emotional support)



These services include:

- 1) improved Spanish craniofacial educational materials for the welcome packet and for the CFC waiting room
- 2) Provision of a Spanish video about cleft care to be viewed during clinic hours
- 3) Development of a Latino family support group for social development
- 4) Exposure of parents to the statewide services of the Family Support Network of North Carolina (FSN-NC) to provide alliances between families with similar experiences, in the form of local parent-to-parent pairings or local support groups

### *Needs Assessment*

The need for concerted efforts to improve Spanish support services is illuminated by the social isolation and unpreparedness among the North Carolina Latino parents needing craniofacial services. Craniofacial literature has repeatedly pointed to limitations in caring for patients from different cultural and social backgrounds.<sup>47,9,28,17</sup> Providers at UNC CFC have noticed a lack of understanding of the health care system, poor social networks, and a lack of understanding of etiology of cleft lip and palate among the Latino patient families seen at the clinic, indicating that the need for more comprehensive care exists on a local level.

The incidence of cleft lip and/or palate among Latinos in North Carolina is not definitively known. Clefting for South Americans is known, but not for transplants from multiple areas. Estimates of orofacial clefts are around 166 per 100,000 live births for North Carolina Latinos.<sup>48</sup> U.S. estimates for cleft lip and/or palate among Latinos range from 74 to 162 per 100,000.<sup>49</sup> Latinos have rates of cleft lip and/or palate less than rates of persons of Caucasian or Asian descent, but more than rates of African Americans. Latinos have the highest

rate of cleft lip *and* palate *with* multiple congenital anomalies of unknown etiology among all ethnic groups.

With high rates of clefting and congenital anomalies among Latinos as well as continual growth of this population in North Carolina, the provision of culturally appropriate care is essential. The language services provided by a health team can directly affect the quality of care received by minorities.<sup>50</sup> Language barriers affect discussions of symptoms, test results, therapies and side effects, adherence to treatment, and any psychosocial concerns. Without an interpreter, providers often rely on family members, friends, or strangers to relay messages to and from the patient. This can result in gross inadequacies of translation, with up to 31 errors per clinical encounter.<sup>51</sup> Also, patients may consider the use of a stranger or a child as an interpreter as a loss of privacy or of dignity.<sup>24</sup> Even the presence of a Spanish interpreter does not guarantee perfect communication between the provider and patient. The most common type of interpretation error, omissions of spoken dialogue, can have severe consequences for the patient.<sup>51</sup> The presence of an experienced interpreter can be a valuable tool, resulting in many less errors in communication. UNC CFC has one such interpreter, trained in medical, and specifically craniofacial, terminology. The UNC CFC survey demonstrated that most of the families felt that the interpretation in this clinic was adequate to understand craniofacial team instructions.<sup>4</sup> Future Latino patient growth or increased interpreter responsibilities may indicate the need for another interpreter at the clinic.

Although the family unit serves as the primary support group for most Latino families, larger or more similar networks may be helpful to support and counsel Latino parents of children with craniofacial differences.<sup>24,31</sup> Latino culture values interdependence versus independence, and much of traditional Latino medicine requires the cooperation of a patients' family and

support system.<sup>25</sup> In the recent survey conducted by Jack/van Aalst et al., 87% of respondents noted that they would be interested in meeting other cleft families, ¾ of whom would prefer to speak with other *Latino* families.<sup>4</sup> The acceptance of such an intervention would therefore be high, and benefits conferred to its participants could include the development of a sense of advocacy, group empowerment, and emotional support.<sup>52</sup> Most Latino parents cited the UNC CFC as the primary support structure for the care of their child, and the establishment of the family support group is an attempt by the CFC to meet Latino family requests to broaden this support.

Written materials in the spoken language are invaluable to the understanding of complicated medical regimens. In the UNC CFC survey, 77% of the participating families felt that the translated educational material was inadequate to prepare them to care for their child.<sup>4</sup> The interpreter at the clinic, through informal conversations, described how most of the Latino patients at the clinic have difficulty reading and understanding the Spanish literature provided to them even when at a low reading level; team members estimate illiteracy rates among the Latino families to be around 30%.<sup>44</sup> The survey conducted by Jack/van Aalst et al., though written in a low reading level of Spanish, required verbal instructions in Spanish for accurate administration. Appropriate educational materials and written instructions are imperative for successful pre- and post-operative care and at-home speech therapy. Follow-up letters, in simplified Spanish, as well as visual aids and videos are useful for Latino families in similar situations.<sup>24</sup> The need for initial educational and supportive materials for parents of newborns with craniofacial differences would be beneficial in eliminating some of the earliest sources of anxiety.

### ***The Political Environment***

The UNC CFC is located in the town of Chapel Hill, which is also the headquarters for the American Cleft Palate-Craniofacial Association (ACPA) and Cleft Palate Foundation (CPF). The town and neighboring communities have personally experienced the influx of Latino families over the past few decades. Practitioners in the clinic remember a time less than 20 years ago when they had no Spanish-speaking patients.<sup>44,53</sup> Because of this and the fact that Latinos are among one of the populations in America with gross health disparities, the proposed Latino craniofacial programs are met with support and enthusiasm among team members. The team itself consists of local program collaborators; all who work within the UNC CFC have passion for craniofacial care and aspire to serve their patients in the best and most comprehensive way.

The UNC CFC functions as an interdisciplinary team with an egalitarian structure; professionals from different disciplines work independently but function collectively to provide the one best outcome for the patients.<sup>28</sup> Often teams such as the UNC Craniofacial team have hierarchical structures in which surgeons provide the ultimate decision-making ability, with input from other necessary subspecialties. In contrast, UNC CFC runs with one team leader each week, which rotates between providers from the specialties of plastic surgery, otolaryngology, psychology, social work, dentistry, and speech therapy. Despite different views among specialists of the specific problems faced by Latino families, all team members encourage increased Latino support services. Craniofacial clinicians and teams over the past 15 years have called for improved educational materials, translator services, and culturally appropriate care for their patients with different cultural characteristics.<sup>9,17,8, 16</sup>

### *Consistency with Local, State, and National Priorities*

The ACPA and CPF are partially funded and supported by the University of North Carolina. As noted in the 2004 ACPA protocol for craniofacial team services, there is a recognized need for provision of linguistically appropriate care for all craniofacial patients, regardless of their cultural background.<sup>26</sup> Within this protocol, it is stated that “It is the responsibility of each [craniofacial] team to be sensitive to linguistic, cultural, ethnic, psychosocial, economical, and physical factors that affect the dynamic relationship between the team and the patient and family.”<sup>26</sup> The ACPA more specifically notes the need for more understandable Spanish educational materials for parents of children with clefts.<sup>9</sup> The CPF provides Spanish cleft educational materials, but has further recognized the need for Spanish materials as evidenced by the ongoing development of a Spanish cleft video (to be released in early 2009). The UNC CFC has reinforced the ACPA’s focus on culturally appropriate care with its recent undertaking of the Latino family survey to identify cultural and linguistic barriers to their care at the clinic.

As North Carolina recognizes its growing Latino population, the barriers for access to health care for this population have become apparent.<sup>54</sup> The lack of linguistically appropriate services plagues this population in addition to financial and transportation barriers. Statewide, priority is shifting towards providing the most culturally appropriate health care for the Latino population.

On a national level, literature flourishes regarding Latino disparities in health care and social services. This literature indicates that language services, cultural differences, poverty, insurance status, and other factors all contribute to the overall difficulty of obtaining adequate care and needed social support resources.<sup>50,51,23,32</sup>

### ***Acceptability***

To be successful, any interventions to improve the overall care provided to Latino patients at UNC CFC must be acceptable to both the team members at the clinic and the families served by such interventions. UNC CFC has shown to be a forward-thinking craniofacial center through the early acknowledgement and recognition of its limitations when providing care to Latino patients. The desire to continually improve the provision of services is apparent from conversations with various team members.<sup>44,53</sup>

Consistent with proposed interventions, 87% of Latino families indicated a desire to speak with other families of cleft children in the 2005-2006 survey.<sup>4</sup> Most of these families specifically desired to speak with other Spanish-speaking families. The previous survey also indicated that most of the participants would benefit from improved Spanish written educational materials to understand further the cause of cleft lip and palate, their child's treatment plan, and at-home care for their child. The professionals who work in the craniofacial clinic can deliver culturally appropriate care when they include these two interventions to supplement the clinical encounter. In accordance with their culture, most Latinos value respect for these professionals as authority figures and have absolute faith in them regardless of how little they understand of required care.<sup>24</sup> An intervention that increases family understanding of cleft care while remaining consistent with cultural values will be most beneficial and accepted.

### ***Financial Resources***

The UNC CFC receives financial support primarily through North Carolina State funding, with about one-sixth of services paid for by Medicaid.<sup>44</sup> Most of the providers in the clinic are employees of the UNC Health System. Clinic tasks outside of the services of the individual team

members include administration, mailing services for the patient families, phone call-back services for Spanish-speaking patients, costs of educational materials provided to families, and the salary of the Spanish interpreter. The surgical care provided by the team for many Latino children is partly financed through Medicaid with the remaining reimbursement through the state fund. However, many of the Latino patients do not have Medicaid, requiring all of the funding to come from the state fund. As the clinic gives many Latinos care that remains uncompensated, the clinic incurs higher costs than it can afford given the current budget.<sup>44,53</sup>

Supplemental funding will be necessary for proposed Latino interventions, to include mailings, additional educational literature, and the acquisition of a Spanish cleft video. Much of the time spent organizing and implementing initial support groups will be from volunteers among the team members, the interpreter, and medical students. The visits with the social worker can encourage and expose the Latino families to the support services provided through FSN-NC, a free service for all families.

### ***Feasibility***

For an intervention to be implementable and sustainable, it must be practical within the given logistical constraints and administrative framework. UNC Medical Center and the Dental School provide the use of their conference rooms for non-operational purposes, such as education and community service opportunities, and can therefore provide the room for a support group. Similarly, local churches or community centers may provide their larger rooms for the use of such a group. The UNC Medical Center also considers it a responsibility to educate the families of the patients, to include health management and self-care through support groups.<sup>55</sup> With this program in place, staffing could remain the same, as the Spanish advocate-interpreter

would be willing to orchestrate the activities of the support group and volunteers could watch the children during these meetings. The key to providing sustainable support networks will reside in the fostering of social support and leadership among the Latino families.

Using grant money or other funding, the clinic can purchase better Spanish educational materials through the CPF. As most of the supplemental support will be social and educational, there are no requirements for additional patient billings. The nature of these services is such that a set number of patient families are not required to make the effort cost-effective. The parent-to-parent pairings and educational video viewings can feasibly occur during regular clinic times as part of a new clinic protocol.

### ***Collaborators / Stakeholders***

The primary stakeholders for a plan to develop supplemental services for Latino patients at UNC CFC would be the providers already caring for these patients. When a child and family feel fully supported concerning their cleft care, their providers benefit as well. Supplemental services such as improved Spanish educational materials will provide the patient families with the education needed to maximize the benefits of the interdisciplinary care. Support groups and parent networking for the Latino patients would empower the patients with a collective advocacy that translates into fuller participation in their children's care. These practitioners have identified that improved Latino services are not only welcome, but they are necessary to continue to serve this growing population.

Other stakeholders in the plan are the patient families themselves. The families have indicated a need for many of the suggested services through the survey conducted in 2005.<sup>4</sup> For the program to be successful, many families would need to desire a change in their approach to



the health care system and the social setting of their child's care. Families must realize that optimal care for their children accompanies improved involvement on their behalf. Once the families acknowledge this, they become critical stakeholders in the program plan. The sustainability of the support groups with inclusion of new Latino cleft families will require the Latino participants to delegate and rotate leadership positions within the support group.

The FSN-NC exists as a state-wide database and central network of social support resources for families of children with special needs.<sup>56</sup> This network has a central office in Chapel Hill, North Carolina, with regional offices throughout the state. Families of children with special needs, including cleft lip and/or palate, Down Syndrome, or prematurity, can call the central office Spanish phone line and receive information about services in their community. While many counties in North Carolina are still deficient in Spanish services, several areas offer Spanish support groups or parent-to-parent pairings specific for craniofacial care (see Appendix for listing of services). This resource can be utilized by any of the Latino patients seen at the UNC CFC, as parents are welcome to join the existing support groups even if they do not reside in the county in which services are offered.

Other organizations external to craniofacial care teams have goals similar to the objectives of the Latino services at the UNC CFC. For one, Latino churches in the area continue to donate funds for Latino craniofacial surgical services. With Latinos being the largest minority in the United States, most health care systems currently and continuously are adapting their programs to become more Latino-friendly. UNC Hospitals as well as other subspecialty care centers may be currently reviewing their own Latino support efforts with the goal for future implementation of Latino empowerment programs. Collaboration within the UNC Health Care

system may circulate this program model to provide a more holistic and sustainable approach to Latino health care acquisition.

### ***Challenges***

One of the most anticipated challenges for the implementation of the program will involve motivating Latino patient families to volunteer as liaisons and role models for other Latino craniofacial parents. Many of the social differences of this population are due to particular social and support-seeking behaviors, which are influenced by many various factors. Simply informing patients of a Latino support group may not be enough to motivate families to attend. Similarly, attendance at the support group does not necessarily amount to participation and volunteering within the group. Participation, ultimately leading to leadership and independence, is necessary for an intervention such as a support group to influence social behaviors and coping outcomes.

A logistical challenge towards implementation of a support group will be finding a convenient time and location for meetings. With many of the families working long hours and with the long distances traveled by most families for clinic days, asking a family to stay another few hours for more discussion may be too taxing. Similarly, providing a support group on a Saturday or Sunday may interfere with family or religious time in the eyes of the participant. Though ultimately the goal is to have a sustainable family-led support group, this may not be feasible in the first year when families are just beginning to get comfortable with their new, more involved roles as caregivers. If family-led support groups eventually become sustainable, it is possible that the location of the support group will need to relocate to outside of the UNC Health Care setting to a more central location in the state, such as Wake County where the majority of

the center's Latino patients live. However, the prevalence of craniofacial anomalies among Latinos is small enough that it is unlikely that support groups in local communities will have enough Spanish-speaking members to sustain regular meetings.

Parent-to-parent pairings will ease the transition for a family with a new cleft child. Challenges to providing this support will initially include gathering volunteers to serve as the more experienced, or "veteran," parent volunteers. Another challenge will be parent volunteers who fail to initiate contact with their matched parent.<sup>36</sup> The effort required to attend a support group and participate in a parent-to-parent pairing may actually increase the stresses of these time- and resource-poor families. Other barriers will include long distances between the families, phone bills, lost phone numbers, and negligent parent follow-up.<sup>10</sup> New families, if interested, should incorporate into the Latino support system well before their first diagnostic visit with the craniofacial team. Latino parents who volunteer at support groups may serve as the initial liaison between the new families and the world of craniofacial care and support.

Because all providers within UNC CFC will benefit from improved services provided to their patients, it is unlikely that providers will disagree with its implementation. However, a full-scale intervention to change social disparities will require providers to become advocates for their Latino families. As noted earlier, it is realistic to assume that initial support group meetings will require meeting space in the UNC Medical Center or Dental School as well as staff members to organize and motivate discussion. The team must acknowledge and accept that clinic funds initially may be required to support the program implementation.

To acquire and disseminate improved Spanish educational materials, there is an assumption that better Spanish literature exists and is available for distribution. However, as evidenced by Edwards and Bonilla, most craniofacial clinics face challenges finding well-

translated and thorough Spanish educational literature.<sup>9</sup> As many team members have recognized, the only available Spanish literature is difficult for many Latino parents with low reading levels to understand, and an estimated one quarter of families, neither parent is literate.<sup>44,57</sup> Similarly, craniofacial anomaly educational videos must be appropriate and concise to consider showing at the clinic.

Challenges inherent to any program plan will involve the collaboration of various stakeholders in the program for brainstorming and critical thinking of the program's objectives and goals. The plan should incorporate this information with any published literature regarding successful Latino family advocacy programs. Another challenge will be developing sustainability for the interventions planned. Without sustainability, a program is merely an activity and not a means to an actual goal, which will take much more time.

## **Program Theory**

Having a child with a health condition requiring complex care can become a significant source of stress for a parent.<sup>7</sup> Coping with this stress and adapting to different daily requirements are imperative for the proper adjustment of the family.<sup>31</sup> Many parents, when faced with such a challenge, develop effective coping strategies through self-education and social support. However, parents that either do not have the capacity to find such resources or are limited by linguistic, financial, and social barriers often sense isolation, grief, and anxiety.<sup>6</sup> This section describes two broad program theories that can be applied to the UNC CFC Latino support program.

### ***ABCX Theory***

The ABCX model, originally proposed by Hill in 1949, is a generic theory of parental coping and stress.

$$\mathbf{A \text{ (event)} + B \text{ (resources)} + C \text{ (interpretation)} \rightarrow X \text{ (reaction)}}$$

In this model, an event occurs such as having a child with a craniofacial difference (A), which interacts with and is mitigated by a family's resources (B) and with the family's cultural interpretation of this event (C) to lead to the family's coping reaction (X).<sup>42,58</sup> This model potentially explains the differences in family responses to having a child with a disability. Culture greatly influences a family's interpretation of an event such as having a child with a cleft (C); culture, intertwined with socioeconomic status, often determines the amount of resources a family has (B). By increasing the family's resources (through informational support and social services education) and by augmenting proper interpretation of the family's situation (through the social support programs), the UNC CFC can encourage a more positive reaction to the stress (X). This theory suggests that informative support and social support are key resources to effective adaptation to new life stresses, such as having a child with a disability. The resources (B) obtained through these supports include problem solving and behavior management skills, negotiation and communication skills when interacting with providers, informal social support, and community support. It is through the provision of properly translated Spanish craniofacial educational materials, appropriate Spanish craniofacial videos, a parent-to-parent support network, and a Latino family support group, that all components of this coping theory intermingle for the benefit of the family.

The development of supplemental and improved craniofacial services for Latino families, in theory, will increase this population's social functioning, familial advocacy, and inter-family

interactions. Social networking and self-help among many of the Latino families suffers because of a lack of understanding of the health care system and recent relocation to a new environment. Multiple dimensions of forces influence health behaviors, creating these barriers to optimal care. The variety of proposed interventions individually and collectively will address several of these influences, and program theories will give the framework for planning interventions.

### *Ecological Perspective*

To understand why Latino patients and families are not finding adequate support with respect to their child's condition, there must be an acknowledgement of the multiple contributing forces hindering support-seeking behavior. According to the ecological perspective, forces act on an individual, interpersonal, organizational, community, and public policy level to influence one's behavior (or a family's behavior).<sup>59</sup> To organize a targeted intervention that will change the health behavior of this population, a close inspection of these individual forces is necessary. These interventions should aim to modify one or several of the influences in order to impart change.

**Individual Level** At the individual level, patient families have particular behaviors that keep them from seeking social and informational support. One theory of cognitive adaptation for individual-level adjustment to stressful events (having a child with a craniofacial malformation) includes three domains: attribution of a cause to an event, establishment of a sense of mastery over the event or over one's life in general, and enhancement of one's self esteem.<sup>60</sup> The support programs planned for Latino parents by the UNC CFC can contribute to each of these three domains and encourage appropriate adaptation to the stress of a child with a craniofacial difference. Control over the event can occur when the parent learns about the condition

(informational control) and takes action to improve the situation (e.g., volunteers for other parents).<sup>58</sup>

Two types of family support services are necessary for cognitive adaptation to a stressful situation, namely social support groups and family education with informational services.<sup>58</sup> Support groups use others to validate the feelings of the individual, and often enhance self-esteem. Parents can make comparisons, share positive encouragement, and aid other parents to achieve control and empowerment through group accomplishments. Educational and informational services provided to families can increase feelings of competence and teach problem-solving, ultimately providing parent empowerment and mastery over their situation.

The Health Belief Model is a psychological model describing the likelihood that an individual will adopt a particular health behavior, and takes into account this individual's beliefs about the behavior and its benefits.<sup>61</sup> This model fosters the development of interventions that can address individual beliefs to influence the behaviors of families. The survey by Jack/van Aalst et al. at UNC CFC identified personal beliefs and perceived barriers that partly explain this population's behaviors.<sup>4</sup> The support group can become a forum for dissemination of information regarding the importance of familial involvement, trust in the UNC CFC, and community support of other Latino families.

**Interpersonal Level** At the interpersonal level, families may fear exposing their social, economic, and educational vulnerabilities to people outside of their families. They also may have fears of deportation if they live in the United States as undocumented workers. These kinds of beliefs may keep a family from engaging in social support systems available to them. Attempts to avoid potential interactions with law and immigration enforcement will minimize their perceived risk, but also isolates the family from parents experiencing similar difficult

experiences. If the clinic supplements the improved educational materials with a support group, it can change the social environment of the Latino families to support positive behavior change and increase involvement in the child's care. According to the theory of behavioral capability, patient families need to be education in how to effectively care for their child.<sup>60</sup> Observational learning, through modeling exercises in support groups or one-on-one with a veteran parent, will teach families what to expect as a child grows. Patient families will be more likely to change social behavior if they feel empowered, develop goals for their child's care, and create high outcome expectancies.

Thoits explained how interpersonal informative support from a group is invaluable to ease the adaptation and transition for families with a child with a malformation such as cleft lip and/or palate.<sup>31</sup> While family and friends may continue to assist the parents, the perceived sameness of daily experiences shared between members of a support group or between parent pairings gives the referred parent true encouragement. This perceived sameness allows the parent to recognize advice as credible and salient.<sup>32</sup> These networks function to enhance and supplement each parent's individual coping strategy. This social scheme allows parents to support and listen to one another without any feelings of obligation or guilt, unlike family and friends from the parents' other social networks.<sup>31</sup> Social supports are less successful when the parents do not perceive similarity between themselves or their situations.<sup>10</sup>

**Organizational and Community Levels** At the organizational and community levels, efforts to change behavior will broaden to include goals such as support, empowerment, and community competency.<sup>61</sup> Organizationally, the Latino families in general may find difficulty scheduling an appointment, finding transportation to their appointments, and understanding all of the information presented to them because of cultural or linguistic barriers. The Spanish



voicemail line and appointment reminder phone calls are organizational interventions that have addressed some of these issues. Affecting behavior by changing the organizational barriers complements behavior changes at the individual and interpersonal levels.

Coatsworth examined the theory behind a similar family intervention aimed to empower immigrant Latino parents living in an impoverished area of Los Angeles via a parent-support network.<sup>6</sup> This intervention is supported by an ecological-developmental theory and the fact that any intervention proposed must have relevant cultural context and incorporate the family. Through family-centered Spanish-speaking support groups, informational support, and parent-to-parent networking, the UNC CFC Latino support program can meet these tenets to provide a successful intervention.

The community level of influence includes the social networks that exist among other families similar to the Latino craniofacial families. Without an identifiable community among other families needing UNC CFC services, families can feel powerless within the health care system as well as within their community outside of the hospital. Latino families may identify with other Latinos in their home community, but the unique situation of having a child with a craniofacial malformation may disengage families from this support system. Most of the families in the recent survey indicated that the UNC CFC served as their primary support system, but a culturally similar support group arisen from clinic population may provide needed additional support. Support groups will identify resources through shared needs that the entire community can utilize, and develop encouraging behaviors for all of the Latino craniofacial patients.

## Logic Model

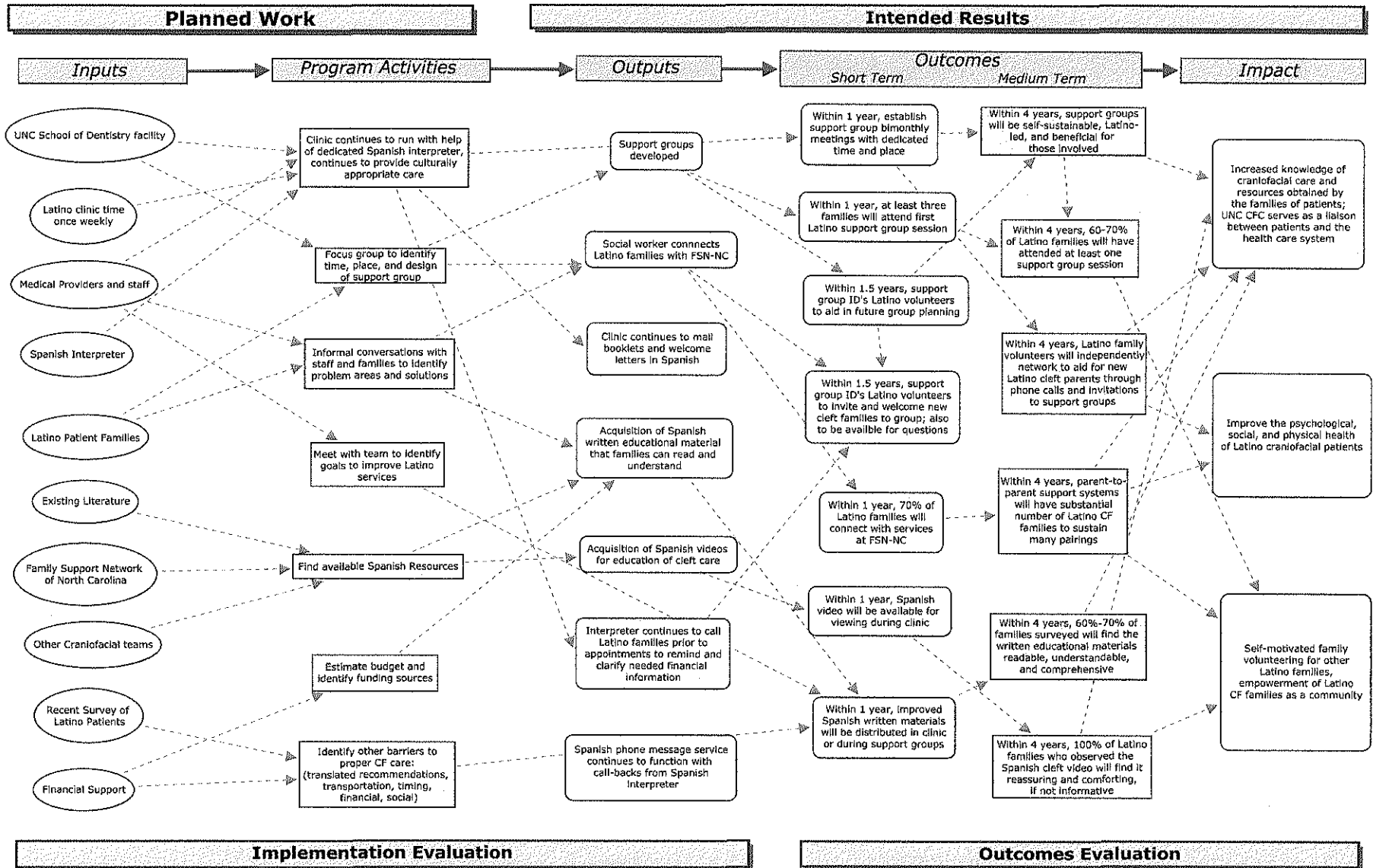
The logic model was developed with input from various stakeholders, including staff from the UNC CFC, patient families, and the Spanish interpreter. Its developmental phases each helped to specify and clarify intended objectives and goals of the program, as well as identify missing components of the activities. It consists of the resources, or inputs, required to begin the program, the activities that will be part of the program, the outputs of those activities, and short-, medium-, and long-term outcomes (or goals).

The primary targets of the intervention are the Latino parents, with secondary benefits for their children. The primary actors in the program are the Latino parents as well, with initial moderation from the Spanish interpreter/advocate and another dedicated UNC CFC staff member. The goal of implementing supplemental and improved Latino services at the UNC CFC is to increase self-motivated family volunteering for other Latino families and to empower the Latino craniofacial families as a community by addressing their social, emotional, and informational support disparities. To increase informational support, strategies will include the provision of Spanish brochures about cleft lip and/or palate as well as viewings of a Spanish cleft lip and/or palate video during clinic time. To increase social support, the program will involve the Latino patients seen at the clinic with parent-to-parent networks through FSN-NC and will develop a regular Spanish support group.

As mentioned previously, a major assumption for this logic model is that the Latino families will voluntarily utilize these services. The barriers that have prevented prior development of a Latino support group are much the same as the barriers that may potentially keep this one from being successful.

This logic model clearly indicates two evaluation endpoints. One occurs at the ‘outputs’ phase, at which point we can evaluate processes as an implementation evaluation. Another occurs at the end of the long-term outcomes, which will evaluate the overall goals of the program as part of a summative or outcomes evaluation.

## Logic Model for Latino Patient Services at University of North Carolina Craniofacial Center



## **Goals and Objectives**

The goal of implementing supplemental and improved Latino services at the UNC CFC is to increase self-motivated family volunteering for other Latino families and to empower the Latino craniofacial families as a community by addressing their social, emotional, and informational support disparities. Currently:

- A Spanish interpreter continues to be available to call Spanish-speaking patients to clarify appointment times and required information for diagnostic clinic visits.
- A Spanish interpreter continues to receive voice messages from the Spanish phone line twice weekly, and returns phone calls after clarifying the requested information with providers.
- The providers continue to provide culturally appropriate care with proper use of the interpreter during clinic visits.
- The clinic continues to mail clinic booklets and welcome letters in Spanish before the families' first diagnostic appointment.

### ***Short Term Objectives: 1-3 Years***

**Informational support objectives:** (All objectives here should be provided at an appropriate reading level based on typical educational attainment)

- Within 1 year, improved and appropriate Spanish cleft care educational materials will be available in written format for distribution during clinic visits and/or support groups.
- Within 1 year, a video with Spanish educational messages about cleft and craniofacial care will be available for viewing during clinic hours in a room available and near to the clinic.

**Social support objectives:**

- Within 1 year, a social worker will connect 70% of Latino families interested with the FSN-NC.
- Within 1 year, through provider involvement as well as feedback from a Latino family focus group, a support group will be established.

- Within 1.5 years, at least three families will attend each Latino support group session.
- Within 1.5 years, the support group will identify Latino family volunteers to aid in future support group planning.
- Within 1.5 years, the support group will identify rotating Latino family volunteers to invite and welcome new craniofacial families to the support group, as well as be available for questions until the CF team pairs the parent with another parent.

***Long Term Objectives: 4-6 Years***

- Informational support objectives:
  - Within 4 years, 60% of Latino families will find the written Spanish educational materials readable, understandable, and comprehensive to answer most treatment questions regarding their child\*.
  - Within 4 years, 100% of Latino families who observed the Spanish cleft video will find it reassuring and comforting and informative.
- Social support objectives:
  - Within 4 years, Latino family volunteers will independently network to aid for Latino parents with a new child with a craniofacial malformation, through phone calls and invitations to support groups (knowledge of these new parents, with their permission, will be provided to Latino volunteers).
  - Within 4 years, regular support group sessions will be self-sustainable, Latino-led, and evaluated as beneficial for those families involved.
  - Within 4 years, 60-70% of Latino families will have attended at least one support group session.
  - Within 4 years, parent-to-parent support systems will have a substantial number of Latino craniofacial families to sustain parent pairings.

(Caveat: due to the migrant nature of much of this population, with high rates of movement and/or deportation, it is unrealistic to achieve high follow-up rates.)

\*Illiteracy rates in this population approach 30%

## Implementation Plan

The development of supplemental Latino craniofacial care services and materials will improve Latino family informational and social support systems for their children with clefts, as well as for other Latino craniofacial families.

### *Activities*

#### Existing Activities

- Spanish craniofacial interpreter present for all diagnostic clinic visits
- Spanish voice message number with interpreter returning calls twice weekly
- Initial diagnostic visit packet mailed to Latino patients with inclusion of Spanish welcome letter and Spanish clinic booklet
- Provider awareness of the proper clinical discussions with use of an interpreter
- Preliminary UNC CFC Latino family focus group

#### Planned Activities

##### *Informational Support:*

- Distribution of educational materials in Spanish
  - Educational materials available on as-needed basis
- Viewing of craniofacial video in Spanish during diagnostic clinic visit.
  - Video viewing either continuously in waiting room or as a station as part of the day's activities
- Attainment of educational booklets in Spanish through the Cleft Palate Foundation for distribution during support group sessions or during clinic visits

##### *Social/Emotional Support:*

- Development of bimonthly Latino support group for both families and children
  - Support groups to be located in a conference room within UNC Health system
  - Groups overseen by interpreter who organizes initial social activity

- Medical student volunteers watch children in conference room corner to free parents of this responsibility
- Encourage Latino parent leadership for the future planning of support groups
  - Latino leadership is essential for the sustainability of support groups over time
- Enlist rotating Latino parent volunteers to serve as initial liaison for new craniofacial families identified through the team
  - These volunteers will contact new Latino families by phone, invite them to upcoming support group meetings, and address questions and concerns raised by the family
- Coordinate families to become involved in Family Support Network of North Carolina (FSN-NC) (see FSN-NC information sheet in Appendix)
  - Inform parents of the state-wide network at initial diagnostic visit
  - Give the mother the phone number of the Spanish-speaking coordinator at the state-wide office
  - Encourage all Latino parents seen at the clinic to call and enroll – if they are from a county that does not have Spanish services, tell of the Spanish-support groups that are available in other counties

### ***Resources for Latino Service Implementation***

- Support Group
  - Room with capacity of 50 or more with food allowance
  - Television with DVD player available for video viewings
  - Staff:
    - Interpreter
    - Volunteer child watchers (medical students)
    - Team member (volunteer)
  - Mailed informative letters to Latino patients in Spanish
    - Include return envelopes for RSVP with due date and request for current phone number
    - Include maps of location
    - Include parking information



- Include the importance that this is family-oriented, to bring children, and the option to bring food
  - Include the phone message line for questions
- Reminder calling system one week prior to session
- Email reminders to medical student volunteers and team member volunteer
- Educational materials for distribution
- Games for children to play
- Obtain parking passes for patient families
- Provide paper and pens at meeting so families can exchange information and phone numbers
- Statewide Network: Family Support Network of North Carolina
  - Orient parents with Fern Gardner, the Spanish resource for FSN-NC at 800-852-0042
  - Some counties have programs, some do not
- Written Educational Materials
  - Cleft Palate Foundation documents and fact sheets
  - Spanish craniofacial feeding sheets
  - Copier and paper
- Spanish Craniofacial Video
  - Free video, Understanding Cleft Lip & Palate: A Guide for New Parents, supplied by Foundation for Faces of Children (in Spanish)
  - Viewing area in clinic (or nearby room where parents can sit)
  - Television and DVD player
- Phone Message System
  - Message system itself
  - Delivery of this number to Latino patients
  - Twice weekly, interpreter checks messages and returns calls
- Interpreter Salary
  - Includes functioning as advocate, actual time spent interpreting, and time spent returning patient calls

# Latino Support Program Evaluation Strategy

## Introduction and Approach to Evaluation

This evaluation will demonstrate the obstacles and successes of a culturally appropriate support program for Latino parents of children with craniofacial differences. While previous reports have demonstrated successes of similar support programs, they often have primarily focused on Caucasian families. The inherent variations between this population and the Latino population, both from cultural beliefs and different expectations, are bound to influence the efficacy of such programs when applied to Latino parents. This evaluation will provide future direction for the program, and will be used by the program coordinators who seek to improve existing services. As the program becomes more successful and effective, it may serve as a model for Latino support program development in other areas. It may highlight needed resources that could be provided by individual institutions or that can be provided by the national organizations providing craniofacial services. This evaluation will aid improvement attempts and can also demonstrate effectiveness of the program, balancing “the need to prove with the need to improve.”<sup>62</sup> An evaluation of the support attempts made by the UNC CFC will demonstrate effectiveness and determine if the program should be continued, expanded, or redirected. It can lead to future funding, external dissemination to other communities or clinics, and to publication of the results.

**Evaluator role** The role of the evaluator will be to provide an unbiased and objective interpretation of the achievements of the support program. While an external evaluator can ideally perform this task, there are few if any funds to support this professional task. An internal evaluator will naturally be biased by his or her dual role as a stakeholder in the program.

However, this is the most feasible person to complete the task of evaluation. Any evaluator of the program, regardless of whom, must have communication and negotiation skills, be flexible, adaptable, and have some experience with prior research or evaluations.<sup>62</sup>

**Stakeholder input** Stakeholders in the program, such as the Spanish interpreter, the families, and involved craniofacial team members, must be included in the design of the evaluation. It is imperative for the evaluator to acquire input from the stakeholders to determine what questions should be answered by the evaluation. This will maximize the utility of the future evaluation results for those involved. Each stakeholder may focus on different questions within the evaluation that are important to determine the functionality and effectiveness of the program. Similarly, involving the stakeholders will encourage their full participation in any evaluation steps that may require their feedback. If the evaluation will somehow affect the tasks performed by the stakeholders, it becomes even more important to have them involved from the beginning.

## **Overview of the Evaluation**

Because the Latino family support program is in the planning stage, this evaluation will primarily utilize a formative evaluation design, to determine how effectively the program is developed. This can include evaluation methods that verify how the program is functioning, and what barriers were encountered in its implementation. To evaluate in this way, quantitative measures, such as the absolute number of parent participants, as well as qualitative measures, through focus groups or informal interviews with stakeholders, can broaden the overall evaluation. Future evaluation designs for the program, after it has been in place for several years,

can evaluate outcome measures such as parental empowerment, perceived social support, and parental volunteering capabilities. To do this type of summative evaluation, the evaluator can utilize time-series analysis of parents before and after involvement in the program utilizing cross-sectional surveys (a quasi-experimental design), as well as Latino parent focus groups. The use of an experimental design with random selection for intervention is unlikely to be feasible, financially reasonable, or comprehensive to demonstrate the scope of the program's effects.

In another context, this program could also be evaluated in the form of a community intervention case study, as this is a unique population but a common intervention. This will allow for "an exploration of community characteristics and how these may influence program implementation, as well as identifying barriers to and facilitators of change"<sup>63</sup>.

The ultimate goal of this evaluation is to be useful for the stakeholders and to result in an efficient and successful support program. In addition to stressing the importance of utility for the evaluation, it also should be feasibly designed within an appropriate time frame and with limited resources. The evaluation also must be accurate, with valid and reliable results, examining the experiences of the participants and of the coordinators.<sup>63</sup> A triangulation of results, using mixed methods, can contribute to a comprehensive and reliable evaluation. Mixed methods of evaluation, using qualitative and potentially quantitative methods, will provide the "richest and most comprehensive description of participants, processes, and outcomes," and will increase credibility to demonstrate utility of the program.<sup>64</sup>

## Evaluation Study Design and Methods

The study designs utilized to evaluate the Latino support program will include observational, descriptive and quasi-experimental designs. Observational design will qualitatively and descriptively evaluate the implementation phase of the program, i.e. whether or not the program delivered the intended services, how many families received the services, how the services were received, etc. The methods for achieving an evaluation with this design will utilize focus groups, activity logs, records of participation, sessions held, and booklets distributed. Quasi-experimental design comprises the future outcomes evaluation, years after the program has been in place, and will use both qualitative and quantitative methods. These methods include pre- and post-intervention surveys of the participants as well as focus groups and informal interviews with participants and staff.

## Evaluation Planning Tables

### Short Term *Informational Support* Objective 1:

Within 1 year, the information in the initial packet for Latino families will include travel, lodging, maps, and consent forms in Spanish.

<b>Evaluation Question</b>	<b>Participant</b>	<b>Evaluation Method</b>
Has the information in the welcome packet been translated?	---	Inspection of the packet
Is the translated material accurate?	Spanish interpreter	Verification of accuracy and similarity between Spanish and English versions
How are parents acquiring the new resources?	Latino parents	Latino parent focus group
Is the information understandable?	Latino parents	Latino parent focus group
Is the information in the packet useful?	Spanish interpreter	Survey of Latino families

Does the welcome packet include all desired information?		
What else do parents desire to have included in the welcome packet?		

Short Term *Informational Support* Objective 2:

Within 1 year, improved and appropriate Spanish cleft care educational materials will be available in written format for distribution during clinic visits and/or support groups.

<b>Evaluation Question</b>	<b>Participant</b>	<b>Evaluation Method</b>
Do we have educational materials in Spanish?	---	---
Is the material available for the families?	Latino families UNC CFC staff	Incorporation of pamphlets into initial diagnostic visit, and log of booklets on shelf  Survey of Latino families
How many booklets were distributed?	UNC CFC staff	Booklet count compared to initial supply
Is the material understandable for the families?	Latino families	Latino parent focus group Survey of Latino families
Is the information desired by the families provided through the materials at the clinic, within the support group?	Latino families Spanish interpreter	Latino parent focus group  Survey of Latino families
How can the material be improved?		

Short Term *Informational Support* Objective 3:

Within 1 year, a video with Spanish educational messages about cleft and craniofacial care will be available for viewing during clinic hours in a room available and near to the clinic.

<b>Evaluation Question</b>	<b>Participant</b>	<b>Evaluation Method</b>
Do we have a Spanish video?	----	---
What viewing time and location has been successful?	UNC CFC staff Latino families	Informal interviews with staff
Is the video being viewed by the Latino families at the clinic?	Latino families UNC CFC staff	Log of viewings

How many Latino families have viewed the video?	UNC CFC Staff	
Is the video perceived as helpful for the Latino families?	Latino families	Latino parent focus group Survey of Latino families

Short Term *Social Support* Objective 1:

Within 1 year, a support group will be established.

<b>Evaluation Question</b>	<b>Participant</b>	<b>Evaluation Method</b>
Is there a bi-monthly Latino family support group?	---	---
How are parents hearing about the support group?	Latino parents Support group staff	Latino parent focus group
How many families attend each support group?	Patient families Support group staff	Log
What difficulties were encountered by the parents to attend the group?	Latino parents	Latino parent focus group
What was a motivating reason to attend the support group?	Latino parents	Latino parent focus group Survey of Latino families
What administrative difficulties were encountered in the establishment of the support group?	Support group staff	Informal interviews with staff
What worked well within the support group?	Latino parents Support group staff	Latino parent focus group
What was not well received within the support group?	Latino parents Support group staff	Informal interviews with staff
What else would parents like to have in the support group?	Latino parents	
Is the division of time for activities appropriate within the group?	Latino parents	
Were child-care providers available to watch the children?	---	--

Short Term *Social Support* Objective 2:

Within 1 year, a social worker will connect 70% of Latino families interested with the Family Support Network of North Carolina parent-to-parent network system.

<b>Evaluation Question</b>	<b>Participant</b>	<b>Evaluation Method</b>
How many Latino families seen at the clinic are informed of the NC-P2P system?	Social worker	Patient log
Do the families understand the parent-to-parent system?	Latino families Spanish interpreter	Latino parent focus group
Are the parents calling the FSN-NC Spanish line to be connected with services?	Latino families FSN-NC	Phone calls to FSN-NC central site
How many parents have called the FSN-NC for services?	FSN-NC	
Are services provided in areas and at times that are useful for our patient families?	Latino families	Latino parent focus group
How long are Latino parents waiting to receive a parent match?	Latino families FSN-NC	Phone calls to regional FSN-NC sites Latino parent focus group
Do Latino craniofacial parents find the matches made through FSN-NC helpful?	Latino families	Latino parent focus group
What could be improved with these services?		

Short Term *Social Support* Objective 3:

Within 1.5 years, at least three patient families will attend each Latino support group

<b>Evaluation Question</b>	<b>Participant</b>	<b>Evaluation Method</b>
How many families attended each support group?	--	Log
What were the challenges to encourage patient families to participate?	Latino parents Spanish interpreter Support group coordinators	Latino parent focus group
What worked well to facilitate patient family participation?	Involved team members	Individual interviews with support group coordinators
How can future recruitment at support groups be improved?		Short surveys of involved team members

Short Term *Social Support* Objective 4:

Within 1.5 years, the support group will identify Latino family volunteers to aid in future support group planning.



<b>Evaluation Question</b>	<b>Participant</b>	<b>Evaluation Method</b>
Have any Latino parents volunteered to continue the support program?	---	---
How is the UNC CFC recruiting parent volunteers?	UNC CFC staff	Informal interviews
How many parents have been interested in continuing the support program?	Latino parents	Conversations during support groups
What has been a priority of Latino parent volunteers?	Latino parents Spanish interpreter	
What are the difficulties in acquiring Latino parent volunteers?	Latino parents Support group staff	Informal interviews with support group staff
What help is required by staff outside of what can be provided by Latino parent volunteers?	Latino parents Support group staff	Conversations during support groups
How many Latino volunteer parents are needed for this task?		
What could be improved with this service?		

Short Term *Social Support* Objective 5:

Within 1.5 years, the support group will identify rotating Latino family volunteers to invite and welcome new craniofacial families to the support group, as well as be available for questions until the CF team pairs the parent with another parent.

<b>Evaluation Question</b>	<b>Participant</b>	<b>Evaluation Method</b>
Has a Latino family liaison been established among support group participants?	Support group staff	Conversation with support group staff
Has the liaison connected with new craniofacial families?	Latino parent liaison New craniofacial families	Phone calls to liaison
How much time elapses between the birth of a craniofacial child and connection with a Latino parent liaison?	New Latino parents Latino parent liaison	Phone calls to liaison Phone calls to new parents
Are new families utilizing the connection with liaison parents or with support groups?	Latino parents	Support group log Phone calls to liaison

Is the early connection with another Latino parent perceived as helpful to new parents?	New Latino craniofacial parents	Survey Latino parent focus group
What are the difficulties encountered by the Latino parent volunteer in making this connection with new families?	Latino parent liaison	Phone calls to liaison
How many new families have connected with veteran Latino parents?	Support group staff UNC CFC staff	Informal conversations with staff
How can this service be improved?	Latino parents	Latino parent focus group
Is the Latino liaison able to switch volunteer positions with another parent?	Latino parent liaison Latino parents	Phone calls to liaison Latino parent focus group

Long Term *Social Support* Objective 1:

Within 4 years, Latino family volunteers will independently network to aid Latino parents with a new child with a craniofacial malformation, through phone calls and invitations to support groups (knowledge of these new parents, with their permission, will be provided to Latino volunteers).

<b>Evaluation Question</b>	<b>Participant</b>	<b>Evaluation Method</b>
Are Latino parents continuing to volunteer for other new Latino parents?	Latino liaisons New Latino parents Spanish interpreter	Latino parent focus group Surveys of Latino parents
Does volunteering aid in empowering Latino families?	Latino parents	Pre and post-volunteer empowerment survey
Are the new Latino parents receiving social support from this connection?	New Latino parents	Surveys Latino parent focus group
Are the new Latino parents receiving information support from other Latino parents?	New Latino parents	Surveys Latino parent focus group
What are some of the challenges experienced by the more experienced Latino parents?	Latino parents	Latino parent focus group
What are some of the challenges experienced by the staff?	UNC CFC staff Support group staff	Informal conversations with staff

Are parents satisfied with this support program?	Latino parents	Surveys of program effectiveness
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Long Term *Social Support* Objective 2:

Within 4 years, bi-monthly support group sessions will be self-sustainable, Latino-led, and evaluated as beneficial for those families involved.

<b>Evaluation Question</b>	<b>Participant</b>	<b>Evaluation Method</b>
Are the support groups still maintained on a bi-monthly schedule?	Latino parents Spanish interpreter	Log
How many support group sessions have occurred?	Support group staff	Log
Where are the support groups held?	--	--
Are the support groups providing needed social and informational support for the parents involved?	Latino parents Spanish interpreter	Program survey administered to Latino parents
Is the support group accessible for a majority of the Latino parents?	Latino parents Social worker Spanish interpreter	Informal interviews
Is there something that can be changed to increase participation in the support group?		
Are the support groups seen as beneficial for those involved?	Latino parents Spanish interpreter	Program survey administered to Latino parents
Did the program improve collective community leadership?	Latino parents	
Did the program increase individual parent's capacities to handle difficult situations?	Latino parents	

Long Term *Social Support* Objective 3:

Within 4 years, parent-to-parent support system information (through FSN-NC) is given to all Latino craniofacial parents through their local or nearest available location, and a Latino parent at the clinic encourages participation by other parents.

<b>Evaluation Question</b>	<b>Participant</b>	<b>Evaluation Method</b>
Are parents receiving information about FSN-NC at their diagnostic visits?	Social worker Latino parents	Informal interviews with social worker  Latino parent focus group
Are Latino parents calling the FSN-NC to learn of social supports in their area?	Latino parents	Latino parent focus group
How many Latino parents have called FSN-NC	FSN-NC staff	Phone call to central FSN-NC office for Spanish speakers
What parents are not being helped by the parent-to-parent services?	Latino parents Social worker Spanish interpreter	Informal interviews with social worker  Latino parent focus group
Are Latino parents receiving social services as a result of connections with FSN-NC?	Latino parents	Latino parent focus group
In what ways is FSN-NC not adequate to provide the needed social services?	Latino parents	Latino parent focus group
Is an independent Latino craniofacial parent-to-parent network desired, outside of the networks provided by FSN-NC?	Latino parents	Latino parent focus group
Are the parent pairings through FSN-NC sustainable for the UNC CFC parents?	Latino parents	Latino parent focus group

## **Dissemination Plan**

This evaluation will only be useful if the stakeholders actually receive the synthesis of results to expand and improve the program. Summary reports of the effectiveness of the social support efforts given to the support group staff can lead towards discussions that will improve future implementation. Because a majority of the formative evaluation will be qualitative, the evaluator will code participant responses from focus groups and informal interviews and summarize them for stakeholders and staff.

Anticipating positive, or at least constructive and informative, outcomes from Latino family participants in the support programs, publications or presentations of this topic at national meetings can disseminate the challenges and successes of the program more broadly. This may not only appeal to the national craniofacial associations, such as CPF and ACPA, but also may appeal to other specialty services that are encountering growing numbers of socially isolated Latino parents.

As the projected program will incorporate the services from the FSN-NC, they are an important and original stakeholder that may take special interest in the results of the program. A special report, tailored to the utilization of the parent-to-parent services by the Latino craniofacial families, may be invaluable to the FSN-NC as they strive to expand and improve their services.

The evaluator, or program coordinator, also must disseminate the evaluation to the Latino patient families that were not reached by the program, either because they did not receive any craniofacial services during the time at which the program was promoted, or because they could not attend during the offered sessions. Similarly, other Latino centers in the area as well as health departments state-wide should be made aware of the bi-monthly support group offered through the program. In this way, not just the evaluation, but also the dissemination of the program itself is important after the initial implementation phase.

## Discussion

The Latino support program should be feasible, attainable, and useful for the Latino families seen at the UNC CFC. The Latino population in North Carolina suffers from the lack of social networks as well as from the language barrier.<sup>44, 57</sup> This program follows the theory that coping and management strategies for parents of a child with a craniofacial malformation improve when they receive comprehensive resources to handle the situation.

The program plan described here is one of the few fully developed programs of its kind, designed to increase familial support for Latino families. Other programs have demonstrated the effectiveness of programs aimed at increasing coping support in English-speaking, Caucasian families or Latino families in multigenerational, well-established Latino communities, but this program serves to unite the disjointed and recently immigrated population within North Carolina.<sup>7, 65-67</sup> This model should be followed and shared with other specialties that similarly find their Latino families struggling to find the social and informational services that they need.

Development of programs such as this, if successful, will empower the Latino population and lead to intra-family volunteering. This sense of community fostered through the program can spread to other areas of the families' lives, and ultimately improve their empowerment in other health arenas. Further qualitative research is needed to fully recognize the potential of this or similar Latino support programs. A well conducted evaluation, similar to the one presented in this paper, could demonstrate this program as a novel model to be reproduced in other areas.

This program is limited by the lack of funding for its implementation. Similarly, the initial step to forming these support systems will involve behavioral change on the part of the

Latino parents, which may prove to be difficult as fears of social exposure and economic realities continue to be barriers for this population.

In conclusion, this program model hopes to motivate personnel within the health care field to understand and affect future support of the Latino population. Just as past legislation has led towards mandates of adequate medical translational services for Spanish-speaking patients, this is a step towards a future in which social services should also be equally accessible for all within the United States, regardless of nation of origin or language.<sup>2, 50, 68</sup>

## Resources

1. Aguirre-Molina M, Ramirez A, Ramirez M. Health promotion and disease prevention strategies. *Public Health Reports*. September-October 1993 1993;108(5):559-564.
2. Flores G. The impact of medical interpreter services on the quality of health care: a systematic review. *Medical Care Research and Review*. June 2005 2005;62(3):255-299.
3. North Carolina Minority Health Facts, Hispanics/Latinos: Department of Health and Human Services; 1999:1-6.
4. Jack M, vanAalst JA, Cohen C, et al. Improving Care for Latino craniofacial patients: experience from a North Carolina craniofacial center: University of North Carolina:1-45.
5. Guzman B. The Hispanic Population, Census 2000 Brief. In: Commerce USDo, ed: U.S. Census Bureau; 2001.
6. Coatsworth JD, Pantin H, Szapocznik J. Familias Unidas: A Family-Centered Ecodevelopmental Intervention to Reduce Risk for Problem Behavior among Hispanic Adolescents. *Clinical Child and Family Psychology Review*. 2002;5(2):113-132.
7. Kerr SM, McIntosh JB. Coping when a child has a disability: exploring the impact of parent-to-parent support. *Child Care Health and Development*. 2000;26(4):309-322.
8. Reeve M-E, Groce NE, Persing JA, Magge SN. An international surgical exchange program for children with cleft lip/cleft palate in Manaus, Brazil: Patient and Family Expectations of Outcome. *The Journal of Craniofacial Surgery*. 2004;15(1):170-174.
9. Edwards PD, Bonilla ZE. The use of Spanish language educational materials by American cleft palate-craniofacial association teams. *Cleft Palate-Craniofacial Journal*. 2004;41(6):655-660.
10. Ainbinder JG, Blanchard LW, Singer GHS, et al. A Qualitative Study of Parent to Parent Support for Parents of Children With Special Needs. Vol 23: Soc Ped Psychology; 2002:99-109.
11. Santelli B, Turnbull A, Marquis J, Lerner E. Parent-to-parent programs: A resource for parents and professionals. *Journal of Early Intervention*. 1997;21(1):73-83.
12. Strauss RP, Committee TACP-CAATS. Cleft palate and craniofacial teams in the United States and Canada: a national survey of team organization and standards of care. *Cleft Palate-Craniofacial Journal*. 1998;35(6):473-480.
13. Bill J, Proff P, Bayerlein T, Weingaertner J, Fanghanel J, Reuther J. Treatment of patients with cleft lip, alveolus and palate - a short outline of history and current interdisciplinary treatment approaches. *Journal of Cranio-Maxillofacial Surgery*. 2006;34(Suppl S2):17-21.
14. Margolis H, Fiorelli JS. An applied approach to facilitating interdisciplinary teamwork. *Journal of Rehabilitation*. January/February/March 1984 1984;50(1):13-17.
15. Garwick AW, Kohrman C, Wolman C, Blum R. Families' recommendations for improving services for children with chronic conditions. *Archives of Pediatric and Adolescent Medicine*. 1998;152:440-448.
16. Louw B, Shibambu M, Roemer K. Facilitating cleft palate team participation of culturally diverse families in South Africa. *Cleft Palate-Craniofacial Journal*. 2006;43(1):47-54.
17. Olosoji HO, Ugboko VI, Arotiba GT. Cultural and religious components in Nigerian parents' perceptions of the aetiology of cleft lip and palate: implications for treatment and rehabilitation. *British Journal of Oral and Maxillofacial Surgery*. 2007;45:302-305.
18. Dagher D, Ross E. Approaches of South African traditional healers regarding the treatment of cleft lip and palate. *Cleft Palate-Craniofacial Journal*. 2004;41(5):461-469.
19. Cheng L-RL. Asian-American cultural perspectives on birth defects: focus on cleft palate. *Cleft Palate Journal*. 1990;27(3):294-300.
20. Brewer CA, Suchan TA. Mapping Census 2000: The Geography of U.S. Diversity. In: Bureau USC, ed: Census 2000 Special Reports; 2001.
21. *NC Latino Health, 2003*. Durham, NC: Latino Health Task Force, North Carolina Institute of Medicine, El Pueblo, Inc.; 2003.
22. Martin JA, Hamilton BE, Sutton PD, et al. Births: Final Data for 2005. In: Reports NVS, ed. Vol 56: CDC; 2007.



23. Flores G, Abreu M, Olivar MA, Kastner B. Access barriers to health care for Latino children. *Archives of Pediatric and Adolescent Medicine*. 1998;152:1119-1125.
24. Fisher NL. *Cultural and Ethnic Diversity: A Guide for Genetics Professionals*: Johns Hopkins University Press; 1996.
25. Maduro R. *Curanderismo* and Latino views of disease and curing, in Cross-cultural medicine. *The Western Journal of Medicine*. 1983;139:868-874.
26. Parameters for evaluation and treatment of patients with cleft lip/palate or other craniofacial anomalies. In: Journal CP-C, ed. Vol 30: American Cleft Palate-Craniofacial Association; 1993.
27. Institute of Medicine. *Unequal Treatment: What Healthcare Providers Need to Know About Racial and Ethnic Disparities in Health Care*: National Academy of Sciences; Department of Health and Human Services; 2002.
28. Strauss RP. The organization and delivery of craniofacial health services: the state of the art. *Cleft Palate-Craniofacial Journal*. 1999;36(3):189-195.
29. *Understanding Cleft Lip & Palate: A guide for new parents* [Video]: Foundation for Faces of Children.
30. Hanline MF, Daley SE. Family Coping Strategies and Strengths in Hispanic, African-American, and Caucasian Families of Young Children. *Topics in Early Childhood Special Education*. 1992;12(3):351-366.
31. Thoits PA. Social support as coping assistance. *Journal of consulting and clinical psychology*. 1986;54(4):416-423.
32. Singer GHS, Marquis J, Powers LK, et al. A Multi-Site Evaluation of Parent to Parent Programs for Parents of Children with Disabilities. *Journal of Early Intervention*. 1999.
33. Pelchat D, Lefebvre H, Proulx M, Reidy M. Parental satisfaction with an early family intervention program. *Journal of Perinatal & Neonatal Nursing*. 2004;18(2):128-144.
34. Santelli B. Parent to Parent Programs: Parent Preferences for Support. *Infants and Young Children*. 1996;9(1):53-62.
35. Santelli B, Turnbull A, Marquis J, Lerner E. Parent to Parent Programs: A Unique Form of Mutual Support. *Infants and Young Children*. 1995;8(2):48-57.
36. Silver EJ, Ireys HT, Bauman LJ, Stein REK. Psychological outcomes of a support intervention in mothers of children with ongoing health conditions: The parent-to-parent network. *Journal of Community Psychology*. 1997;25(3):249-264.
37. Preyde M, Ardal F. Effectiveness of a parent "buddy" program for mothers of very preterm infants in a neonatal intensive care unit. *Canadian Medical Association Journal*. 2003;168(8):969-973.
38. Melnyk BM, Alpert-Gillis L, Feinstein NF, et al. Creating opportunities for parent empowerment: program effects on the mental health/coping outcomes of critically ill young children and their mothers. *Pediatrics*. Jun 2004;113(6):e597-607.
39. Melnyk BM, Feinstein N, Fairbanks E. Evidence-based practice. Two decades of evidence to support implementation of the COPE program as standard practice with parents of young unexpectedly hospitalized/critically ill children and premature infants. *Pediatric Nursing*. 2006;32(5):475-481.
40. Pearson J, Andersen K. Evaluation of a program to promote positive parenting in the neonatal intensive care unit. *Neonatal Network*. 2001;20(4):43-48.
41. Singer GHS. Suggestions for a pragmatic program of research on families and disability. *Journal of Special Education*. 2002;36(3):148(147).
42. Harry B. Trends and issues in serving culturally diverse families of children with disabilities. *Journal of Special Education*. 2002;36(3):131(139).
43. Medvene LJ, Mendoza R, Lin K-M, Harris N, Miller M. Increasing Mexican American attendance of support groups for parents of the mentally ill: organizational and psychological factors. *Journal of Community Psychology*. 1995;23:307-325.
44. Strauss RP. Personal communication. Chapel Hill, NC; February 11, 2008.
45. UNC Craniofacial Center Mission. <http://www.dent.unc.edu/patient/clinics/craniofacial/mission.htm>. Accessed February 12, 2008.
46. *Welcome to the UNC Craniofacial Center* [Handbook]: UNC Chapel Hill School of Dentistry Craniofacial Center; 2007.

47. Meyerson MD. Cultural considerations in the treatment of Latinos with craniofacial malformations. *Cleft Palate Journal*. 1990;27(3):279-288.
48. Racial and Ethnic Differences in Health in North Carolina: 2004 Update. Raleigh: N.C. Department of Health and Human Services; State Center for Health Statistics and Office of Minority Health and Health Disparities; 2004.
49. Tolarova MM, Cervenka J. Classification and birth prevalence of orofacial clefts. *American Journal of Medical Genetics*. 1998;75:126-137.
50. Lavizzo-Mourey R. Improving quality of US health care hinges on improving language services. *Journal of General Internal Medicine*. 2007;22(Suppl 2):279-280.
51. Flores G, Laws B, Mayo SJ, et al. Errors in medical interpretation and their potential clinical consequences in pediatric encounters. *Pediatrics*. 2003;111:6-14.
52. Munn-Giddings C, McVicar A. Self-help groups as mutual support: what do carers value? *Health Social Care Community*. 2007;15(1):26-34.
53. Miller V. Personal communication. Chapel Hill, NC; February 18, 2008.
54. North Carolina Minority Health Facts, Hispanics/Latinos. Raleigh: N.C. Department of Health and Human Services; State Center for Health Statistics and Office of Minority Health and Health Disparities; 2006.
55. UNC. Health Care Policy p-8. 2008.
56. Family Support Network of North Carolina. 2003; <http://www.fsnncc.org/home.htm>. Accessed February 2008.
57. Cohen C. Personal Communication. Chapel Hill: Spanish Interpreter; March 30, 2008.
58. Summers JA, Behr SK, Turnbull AP. Adaptation and Coping Strengths of Families Who Have Children with Disabilities. *Support for Caregiving Families: Enabling Positive Adaptation to Disability*. 1989.
59. Glanz K, Rimer B. Theory at a Glance: A Guide for Health Promotion Practice. In: U.S. Department of Health and Human Services NIOH, ed. Second ed: National Cancer Institute; 2005.
60. Taylor S. Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist*. 1983;38(1):161-161.
61. Dickens P. Lesson 6. *Program Planning and Evaluation Class*: University of North Carolina at Chapel Hill School of Public Health.
62. Foundation WKK. *Evaluation Handbook*: WK Kellogg Foundation; 1998.
63. *Introduction to program evaluation for public health programs: a self-study guide*. Atlanta, GA: U.S. Department of Health and Human Services. Centers for Disease Control and Prevention. Office of the Director, Office of Strategy and Innovation; 2005.
64. Potts S. *Evaluation for 1st year grantees*: Arizona State University; November 2000.
65. Levine EB. Toward a Model of Latino Parent Advocacy for Educational Change. *Diverse Families, Competent Families: Innovations in Research and Preventive Intervention Practice*. 2000.
66. Zhang C, Bennett T. Facilitating the meaningful participation of culturally and linguistically diverse families in the IFSP and IEP process. *Focus on Autism and Other Developmental Disabilities*. Spring 2003 2003;18(1):51-59.
67. Hartman AF, Radin MB, McConnell B. Parent-to-parent support: a critical component of health care services for families. *Issues Compr Pediatr Nurs*. Jan-Mar 1992;15(1):55-67.
68. National standards for culturally and linguistically appropriate services in health care, executive summary. In: U.S. Department of Health and Human Services O, Office of Minority Health, ed; 2001.

## Appendix:

**Table 1:**

<b>Evaluation Measures from Literature Review</b>				
<b>Outcome Desired</b>	<b>Test/Measure</b>	<b>Description/Examples</b>	<b>Studies Used (Initial Source)</b>	<b>Validation</b>
Cognitive Adaptation (measure of positive attitudes about a child with a disability in a family)	Source of Strength and Family Closeness Subscale of the Kansas Inventory of Parental Perceptions	"My family has become closer (because of my child with a disability)"	Singer et al., 1999 (KIPP; Behr, Murphy, & Summers, 1992)	Family APGAR (Smilkstein, Ashworth, Clark, & Montano, 1982)
Empowerment (3 domains: Family, Service System, and Community Political)	Family Empowerment Scale	Measures attitudes, knowledge, and behavior "I feel I can solve problems with my child when they happen"	Singer et al., 1999 (Koren, DeChillo, & Friesen, 1992)	Koren DeChillo, Friesen, 1992
Coping Efficacy (2 subscales, Coping with Child and Coping with Family)	Parent Coping Efficacy Scale	"Over the last week, how capable have you felt dealing with your child's day-care or childcare needs?"	Singer et al., 1999 (PCES; Blanchard et al., 1996)	Blanchard, Powers, Ginsberg, Marquis, Singer, 1996
Perceived helpfulness of Parent to Parent	1 question, 4-point Likert scale from 1 ( <i>not helpful</i> ) to 4 ( <i>very helpful</i> )	"Overall how helpful was Parent to Parent?"	Singer et al., 1999	
Stress	Parental Stressor Scale: NICU/PICU	1 (no stress) to 5 (high stress)	Preyde and Ardal, 2003  Melnyk et al., 2004	Miles, Funk, Carlson 1993.
State Anxiety (at the moment)	State Anxiety Inventory	20 (not anxious) to 80 (extremely anxious)	Preyde and Ardal, 2003; Melnyk et al., 2004 (Spielberger et al., 1970)	Spielberger, Gorsuch, Lushene, Vagg, Jacobs 1983
Perceived Social Support	Multidimensional Scale of Perceived Social Support	1 (little support) to 7 (much support)	Preyde and Ardal, 2003 (Zimet et al, 1988)	Zimet, Dahlem, Zimet, Gordon, 1988
Trait Anxiety	Trait Anxiety Inventory	Measures how prone people are to respond to stressful events with anxious reactions	Preyde and Ardal, 2003 (Spielberger et al, 1970)	Spielberger, Gorsuch, Lushene, Vagg, Jacobs 1983

Outcome Desired	Test/Measure	Description/Examples	Studies Used (Initial Source)	Validation
Depression	Short form of Beck Depression Inventory  Depression Subscale, Profile of Mood States	0-16+, with 16+ indicating severe depression	Preyde and Ardal, 2003 (Beck et al, 1961)  Melnyk et al., 2004 (Lorr McNair, 1982)	Reynolds, Gould 1981; Bumberry, Oliver, McClure 1978
Negative mood state	Profile of Mood States, short form		Melnyk et al, 2004 (Lorr, McNair, 1982)	
Parent participation in care	Index of Parent Participation		Melnyk et al, 2004 (Melnyk 1994)	
Psychiatric symptoms (anxiety, depression, anger, cognitive disturbance)	Psychiatric Symptom Index	PSI total scores of 20 or greater reflect "high" symptom levels	Singer et al, 1997 (Ilfeld, 1976)	Stein & Jessop, 1984; Jessop, Riessman, Stein 1988

# English version of UNC CFC Latino survey

## The Impact of Cross-Cultural Issues on Cleft and Craniofacial Care

### The Answers to These Survey Questions will be Used for Research

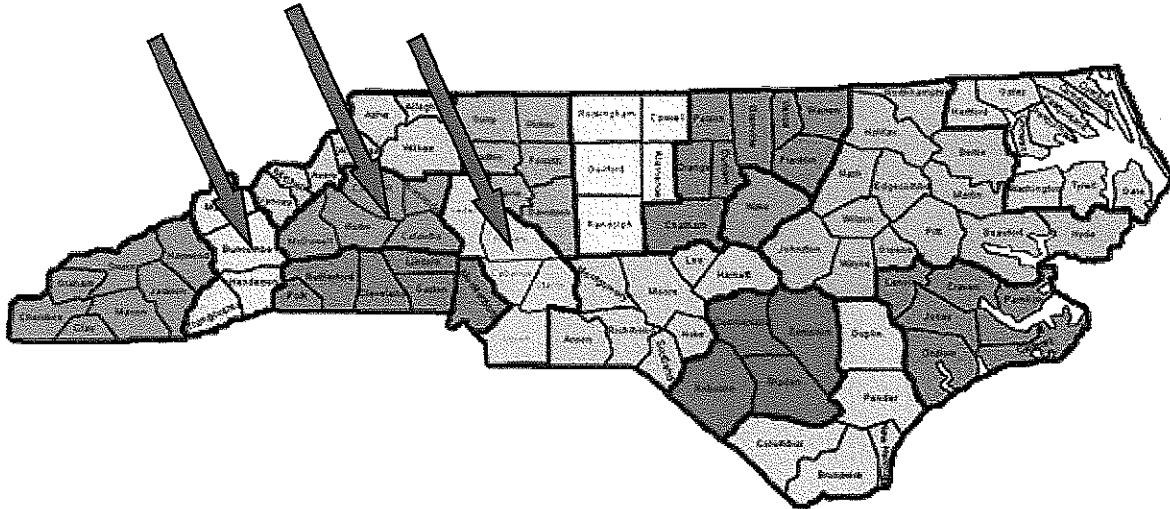
Name of patient: \_\_\_\_\_ Medical Record: \_\_\_\_\_  
 Diagnosis: \_\_\_\_\_ Birth Date: \_\_\_\_\_ Date of Survey: \_\_\_\_\_  
 Place of Birth: \_\_\_\_\_ Person answering questions: \_\_\_\_\_  
 Relation to Child: \_\_\_\_\_ Person administering survey: \_\_\_\_\_

1. How did you find the UNC Craniofacial Center? 1) Pediatrician, 2) Other doctor, 3) Social Worker, 4) Friend, 5) Other; specify: \_\_\_\_\_
2. Do you know anyone else with a child who has a cleft or craniofacial difference? 1) Yes, 2) No; if yes, who? \_\_\_\_\_
3. Do you know anyone in your family with a cleft/craniofacial difference? 1) Yes, 2) No; if yes, who? \_\_\_\_\_
4. Would you like to get to know another family who has a child with a similar difference? 1) Yes, 2) No; explain \_\_\_\_\_
5. Would you be willing to help talk to another family with a child who has a similar difference? 1) Any family, 2) A Spanish speaking family, 3) No thank you
6. Is the UNC Craniofacial Center the first Craniofacial Center to give care to your child? 1) Yes, 2) No; if no, where else? \_\_\_\_\_
7. Was your child's diagnosis made by ultrasound before birth? 1) Yes, 2) No \_\_\_\_\_
8. In what country was the diagnosis made? 1) US, 2) Other country: Where? \_\_\_\_\_
9. Did your child receive care in your home country? 1) Yes, 2) No \_\_\_\_\_
10. Did your child have surgery in your home country? 1) Yes, 2) No \_\_\_\_\_
11. Why did you relocate to North Carolina? 1) Job, 2) Family, 3) Healthcare for your child, 4) Other \_\_\_\_\_
12. How well can mother/guardian understand English? 1 2 3 4 5 (1=Not at All; 5=Very Well)
13. How well can father/guardian understand English? 1 2 3 4 5 (1=Not at All; 5=Very Well)
14. How well can your child understand English? 1 2 3 4 5 (1=Not at All; 5=Very Well)
15. How well can mother/guardian speak English? 1 2 3 4 5 (1=Not at All; 5=Very Well)
16. How well can father/guardian speak English? 1 2 3 4 5 (1=Not at All; 5=Very Well)
17. How well can your child speak English? 1 2 3 4 5 (1=Not at All; 5=Very Well)
18. How well can your child understand Spanish? 1 2 3 4 5 (1=Not at All; 5=Very Well)
19. How well can your child speak Spanish? 1 2 3 4 5 (1=Not at All; 5=Very Well)
20. What language is spoken most at home? 1) English, 2) Spanish, 3) Other \_\_\_\_\_
21. What languages does your child speak most of the time? 1) English, 2) Spanish, 3) Both, 4) Other \_\_\_\_\_
22. Were there any words used at the Craniofacial Center you did not understand? 1) Yes, 2) No; if yes, explain: \_\_\_\_\_
23. Where is patient's father from? 1) Mexico, 2) Central America, 3) South America, 4) Other Country: \_\_\_\_\_; State: \_\_\_\_\_; City: \_\_\_\_\_

24. Where is the patient's mother from? 1) Mexico, 2) Central America, 3) South America, 4) Other \_\_\_\_\_  
Country: \_\_\_\_\_; State: \_\_\_\_\_; City: \_\_\_\_\_
25. Where do you live now? City: \_\_\_\_\_; County: \_\_\_\_\_; State: \_\_\_\_\_
26. Did you know someone in your current town or city before coming to the US? 1) Yes, 2) No  
If yes, was it 1) Family, 2) Friends, 3) Employer, 4) Other, specify: \_\_\_\_\_
27. How long have you lived in North Carolina? \_\_\_\_\_ years/months
28. How long have you lived in the US? \_\_\_\_\_ years/months
29. How many trips did you make to the US before moving to your current town/city? \_\_\_\_\_
30. Where else have you lived in the US? \_\_\_\_\_
31. In what field does the patient's father work? 1) Agriculture, 2) Construction, 3) Restaurant, 4) House cleaning, 5) Medical/business/legal 6) Other \_\_\_\_\_, 7) Not working
32. In what field does the patient's mother work? 1) Agriculture, 2) Construction, 3) Restaurant, 4) House cleaning, 5) Medical/business/legal 6) Other \_\_\_\_\_, 7) Not working
33. How many years did the patient's father go to school? \_\_\_ years
34. How many years did the patient's mother go to school? \_\_\_ years
35. Does the family regularly go to Church? 1) Yes, 2) No
36. What is your religious group? 1) Catholic, 2) Protestant, 3) Other, 4) None \_\_\_\_\_
37. Where do you feel you get the most support for the difference your child has? 1) Church, 2) Family, 3) Friends, 4) Craniofacial Center, 5) Other \_\_\_\_\_
38. What do you think caused the difference in your child? \_\_\_\_\_
39. Are you pleased with care your child received at the UNC Craniofacial Center? 1) Yes, 2) No; rate 1 2 3 4 5 (1 = not very good; 5 = very good) \_\_\_\_\_
40. Are you happy with your child's appearance? 1) Yes, 2) No; rate 1 2 3 4 5 (1 = not happy; 5 = very happy); If not happy, please explain: \_\_\_\_\_
41. How would you rate the care at by the UNC Craniofacial Team? 1 2 3 4 5 (1 = not good; 5 = very good).
42. How well did you understand the UNC Craniofacial Team members? 1 2 3 4 5 (1 = not well; 5 = very well)
43. Did you feel you could ask the questions you wanted? 1) Yes, 2) No  
If no, explain: \_\_\_\_\_
44. Was translation of questions/answers good? 1 2 3 4 5 (1=not good; 5=very good)
45. Who makes most of the health care decisions for your child in the family? 1) Mother, 2) Father, 3) Grandmother, 4) Grandfather, 5) Other \_\_\_\_\_
46. Do you feel that you have adequate printed information in Spanish provided by the Craniofacial Team? 1) Yes, 2) No; if no, explain: \_\_\_\_\_
47. Were all your questions answered by the UNC Craniofacial Team members? 1) Yes, 2) No; if no, explain: \_\_\_\_\_
48. Were you able to have questions answered by phone when you called? 1) Yes, 2) No; if no, explain: \_\_\_\_\_

## FSN-NC Pamphlet:

# North Carolina Latino Support Programs



North Carolina is unique in that it has a semi-centralized statewide Parent-to-Parent network, called **Family Support Network of North Carolina**, with parent matches offered in each county. This network allows parents to be matched on the basis of their child's disability or other demographic factors linking two families. Parents matched this way have a partner parent whom they can call or meet with as a form of social support.

The central office is located in Chapel Hill, and Latino parents can call this office to speak in Spanish with a Latino liaison who can match them with services in their area. Not every county has a Spanish-speaking Parent-to-Parent network, though. Counties are clustered together as shown on the above map. While some county clusters have well-developed Spanish support programs (such as the clusters with the red arrows), other county clusters are just beginning to develop their database of Spanish parents and families.

All Spanish-speaking parents should call **800-852-0042** to speak with the central Spanish representative, **Fernanda Gardner**, to find information about programs in their area.

<b>Counties</b>	<b>Programs Offered</b>	<b>Contact</b>
Alamance		
Alexander (HOPE)	Emotional support, tech support, once monthly dinner and child care, P2P	Spanish: (828) 438-6540 ext. 2 Melanie, Andrea (800) 822-3477
Alleghany, Anson, Ashe, Avery		
Beaufort, Bertie, Bladen, Brunswick		
Buncombe (Western)	P2P with Latino families Latino support group Hendersonville, soon to be in Asheville too, with dinner and childcare	Sylvia Keener 828-694-7975 ext 227 (888) 810-2800 ext. 2
Burke (HOPE)	Emotional support, tech support, once monthly dinner and child care, P2P	Spanish: (828) 438-6540 ext. 2 Melanie, Andrea (800) 822-3477
Cabarrus		
Caldwell (HOPE)	Emotional support, technical support, once monthly dinner and child care, P2P	Spanish callers: (828) 438-6540 ext. 2 Melanie, Andrea (800) 822-3477
Camden, Carteret, Caswell		
Catawba (HOPE)	Emotional support, tech support, once monthly dinner and child care, P2P	Spanish: (828) 438-6540 ext. 2 Melanie, Andrea (800) 822-3477
Chatham, Cherokee, Chowan, Clay, Cleveland, Columbus, Craven, Cumberland, Currituck, Dare		
Davidson (Greater Forsyth)	P2P, with a few Spanish parents	(336) 924-5301 Fern 800-852-0042, Spanish speakers can call
Davie (Greater Forsyth)	P2P, with a few Spanish parents	(336) 924-5301 Fern 800-852-0042, Spanish speakers can call
Duplin, Durham, Edgecombe		
Forsyth (Greater Forsyth)	P2P, with a few Spanish parents	(336) 924-5301 Fern 800-852-0042, Spanish speakers can call
Franklin, Gaston, Gates, Graham, Granville, Greene, Guilford, Halifax, Harnett, Haywood		
Henderson (Western)	P2P with Latino families Latino support group Hendersonville, soon to be in Asheville too, with	Sylvia Keener 828-694-7975 ext 227 (888) 810-2800 ext. 2

	dinner and childcare	
Hertford, Hoke, Hyde, Iredell, Jackson, Johnston, Jones, Lee, Lenoir, Lincoln		
McDowell (HOPE)	Emotional support, tech support, once monthly dinner and child care, P2P	Spanish: (828) 438-6540 ext. 2 Melanie, Andrea (800) 822-3477
Macon		
Madison (Western)	P2P with Latino families Latino support group Hendersonville, soon in Asheville too, with dinner and childcare	Sylvia Keener 828-694-7975 ext 227 (888) 810-2800 ext. 2
Martin, Mecklenburg, Mitchell, Montgomery, Moore, Nash, New Hanover, Northampton, Onslow, Orange, Pamlico, Pasquotank, Pender, Perquimans, Person, Pitt, Polk, Randolph, Richmond, Robeson, Rockingham, Rowan, Rutherford, Sampson, Scotland, Stanly		
Stokes (Greater Forsyth)	P2P, with a few Spanish parents	(336) 924-5301 Fern 800-852-0042, Spanish speakers can call
Surry (Greater Forsyth)	P2P, with a few Spanish parents	(336) 924-5301 Fern 800-852-0042, Spanish speakers can call
Swain		
Transylvania (Western)	P2P with Latino families Latino support group Hendersonville, soon to be in Asheville too, with dinner and childcare	Sylvia Keener 828-694-7975 ext 227 (888) 810-2800 ext. 2
Tyrrell, Union, Vance		
Wake	Limited Latino parent matching P2P	Connect with local program and local health department
Warren, Washington, Watauga, Wayne, Wilkes, Wilson		
Yadkin (Greater Forsyth)	P2P, with a few Spanish parents	(336) 924-5301 Fern 800-852-0042, Spanish speakers can call
Yancey		