

1. PROJECT IDENTIFICATION

Project Title: *Niños Especiales/Familias Fuertes* (Special Children/ Strong Families)

Project Number: H17MC06706

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Project Period: March 2006 – March 2011

Total Amount of Grant Awarded: \$247,043.51

## FINAL REPORT AND ABSTRACT

### Narrative:

#### 1. PURPOSE OF PROJECT AND RELATIONSHIP TO SSA TITLE V MATERNAL AND CHILD HEALTH (MCH) PROGRAMS:

Latino children with special health care needs (CSHCN) may not receive appropriate health care because their parents have difficulty understanding and accessing health services due to language, economic or cultural barriers, and a lack of social support. By definition, CSHCN require more medical care than other children, and they, therefore, require more care from their parents and other family members. For their children to receive appropriate health care, parents of CSHCN must learn to navigate a complex health care system and frequently must advocate against a seemingly unresponsive system for their special needs child to receive necessary services. *Niños Especiales/Familias Fuertes*, a partnership of a community-based health clinic and a faith-based community organization engaged Spanish-speaking families with CSHCN in family advocacy and support groups to provide families with the knowledge and skills to obtain appropriate health care for their children.

Collaboration with the Utah State Title V program and the Utah Chapter of the American Academy of Pediatrics (UAAP) has been very important in the success of *Niños Especiales/Familias Fuertes*. A representative from Utah CSHCN (a Title V program), Barbara Ward, RN, was an active member of our Advisory Board until her retirement. She will be replaced by another representative, with whom we have also worked for many years. We have maintained close contact with the UAAP; Dr. Karen Buchi, an active member of our Advisory

Board and the former Medical Director of South Main Clinic was the President of the organization. We have also partnered with a resident who received a CATCH (Community Access to Child Health) grant from the American Academy of Pediatrics. These linkages have assisted us in finding new opportunities for collaboration and dissemination of our work.

In our second year of funding, we partnered with the Utah Regional Leadership Education in Neuro-developmental Disabilities (URLEND) program, a federally funded program to train health professionals to care for children with neuro-disabilities. In a mutually beneficial partnership, URLEND trainees develop and present modules to our groups from September – April. This relationship has enhanced our partnership with both the Utah Title V MCH Program and the Utah Chapter of the American Academy of Pediatrics, because both of these groups are well represented in URLEND.

## 2. GOALS AND OBJECTIVES:

To meet the need so Latino families with children with special health care needs, the *Niños Especiales/Familias Fuertes* team created the following Goals and objectives:

**Goal 1:** Increase the knowledge of health care needs and resources, advocacy skills, social capital and well being of families of Latino CSHCN.

**Objective 1:** Develop a preventive health curriculum for families based on the general and CSHCN specific (e.g., Down syndrome) AAP health care guidelines.

**Objective 2:** Develop a family health advocacy curriculum for families of Latino

CSHCN.

**Objective 3:** Implement family advocacy groups for 120 Spanish-speaking families with CSHCN.

**Goal 2:** Measure the impact of *Niños Especiales/Familias Fuertes*.

**Objective 1:** Determine baseline adherence to AAP guidelines for preventive services and immunization rates of participating Latino CSHCN.

**Objective 2:** Determine baseline social capital and parental well being using the Social Capital Scale for families raising children with chronic health conditions (SCS) and Medical Outcomes Study Short Form (SF-12v2™) respectively.

**Objective 3:** Compare the guideline adherence measures, immunization rates, SCS and SF-12v2™ scores following participation in the family advocacy groups.

*Niños Especiales/Familias Fuertes* was able to meet the majority of its goals and objectives. Recruiting and maintaining participating families was the biggest challenge throughout the project. These families are already stressed by the burden of having a child with special needs. They often did not have transportation to the clinic and their contact information changed frequently. We tried various things to improve attendance, and found that varying the time of day for meetings worked well. The evening group for socializing was the most popular of all topics and times. In addition, we offered a raffle of a gift card to all participants, a much appreciated incentive for participating. We video-taped all sessions with guest speakers and made copies available to the participants to view in the clinic library, at the clinic or in their

home.

We also needed to adjust our evaluation timeline, due to the difficulty in reaching families and administering the baseline surveys in a timely manner; it took more than 2 years to collect the data for an 18 month period. Fortunately because of a research grant from the Primary Children's Medical Center Foundation, we were able to conduct both a quantitative and qualitative outcome analysis. We used the ongoing analysis to make changes in the program. The quantitative analysis did not show much of a difference between families who attended and who did not attend the groups. The measures we used may not have detected the changes that did occur.

### 3. METHODOLOGY:

To better understand the needs of families with children with special health care needs (CSHCN), Dr. Hobson, the Project Director, conducted a series of studies supported by a Community Access to Child Health (CATCH) grant from the American Academy of Pediatrics (AAP). We surveyed pediatricians in Salt Lake County to determine what referral sites for CSHCN they used. While some relevant resources were utilized, many more that would be appropriate were not. We found that most physicians wanted to know more about these resources. With regard to the Spanish-speaking community, most physicians were unaware of any resources other than the local children's hospital. In addition, the CATCH grant allowed us to survey local organizations to determine the availability of Spanish-speaking services for families of CSHCN. Only a few were identified, and there were no active Spanish-speaking family support groups.

Another aspect of the CATCH grant was to be better understand families of CSHCN and their needs; we conducted a series of focus groups with Spanish and English speaking parents of CSHCN. (See Table One)

**Table One: Results from CATCH focus groups**

Themes	Quotation from Family Members
<b>Isolation</b>	“We feel very alone. It’s hard to live away from your family and also have a child who is ill” “Another problem of immigrants is having no family here in the US. I would like to have my mother here, but it is not possible.”
<b>Need to Speak to Others in Similar Situations</b>	“We talk with friends who don’t have children with special needs, but they don’t understand all the problems we have.” “Sometimes we only need to be heard. My friends listen to me, but they don’t understand because they don’t have children with disabilities.”
<b>Support for Family</b>	“My husband used to get into the closet to cry and I didn’t know how to help him...also our other children need us, but we can’t satisfy all of them.” “I don’t have enough hands to assist all my four children and I can’t leave anyone out.”
<b>Need for Information and Training</b>	“There are things I don’t know how to do because I’m a mother who is learning.” “We haven’t looked for outside help because I don’t know how to find it.”
<b>Cultural and Language Issues</b>	“At home we have two languages present: English and Spanish. Sometimes I don’t understand completely what my child is saying.”

The English-speaking and Spanish-speaking groups expressed many of the same concerns, but the isolation that the Spanish-speaking parents felt was much greater than that expressed by the English-speaking ones. Most of the parents wanted to be able to talk with others whose children were similar to their own. The families spoke of the need to learn about how to cope and how to better care for their children and how they could advocate for themselves and their children. From this discussion came the suggestion for the creation of a discussion, support and advocacy group. Parents expressed the desire to meet somewhere close to their homes, and where their children could not break anything or harm themselves. They agreed that South Main Clinic would be a good place for the groups to meet. From their input, *Niños Especiales/ Familias*

*Fuertes* was conceptualized.

During the focus groups, almost all of the parents reported that they lacked social interaction with other parents of CSHCN. By providing these opportunities, the goal of *Niños Especiales/ Familias Fuertes* was to increase the knowledge, skills and social capital of Latino families of CSHCN, which would improve access to health services and improve outcomes for their children.

First, to better understand all of the low income Latino children in our clinic, we conducted a comparative study to better understand how Spanish-speaking families with and without CSHCN differ. We assessed baseline caregiver and child outcomes for families with and without CSHCN treated at the South Main Clinic. These data allowed us to approximate how similar the NEFF patients are to non-CSHCN families before and after participation. In addition, evaluating the families without CSHCN helped identify barriers common across all families that could be addressed through the NEFF program.

After obtaining ideas and input from families, we created a series of groups that would gather at the clinic at various times of the day to discuss issues relating to raising CSHCN. To make the program low cost and sustainable, we partnered with local organizations to provide the teaching for the groups. We used donated space in our clinic. We found volunteer or low cost child care providers. Other local businesses provided donated food for the groups. The groups met at an average of three times per month. Some families participated in all sessions, some in only one.

We prospectively evaluated the empowerment groups in the NEFF program by comparing the change in caregiver and child outcomes over time. It was not feasible to do a randomized controlled trial in this setting because many of the families at the South Main Clinic already knew one another and contamination of the trial would likely occur through sharing of NEFF resources. In addition, we did not want to deny any families the opportunity to participate in an activity we believed would be helpful. All of the scales and surveys obtained self-reported data from the participants. A research assistant administered the scales and surveys to the families, due to a low level of literacy in the study population. Much of the data was obtained over the phone.

Social capital was assessed using the previously validated Social Capital Scale (SCS) for families raising children with chronic conditions. Developed and tested in 2003, the 20 question survey instrument allows researchers to measure a family's social capital. We also utilized the Social Capital Index (SCI), an index that also measures components of social capital. Caregiver well-being was assessed using the validated SF-12 Health Survey (SF-12v2™). The SF-12v2™ is a 12 question survey that produces data in 8 domains: physical functioning, role limitations due to physical health, bodily pain, general health perceptions, vitality, social functioning, role limitations due to emotional problems, and mental health. Using the Pediatric Quality of Life Inventory (PedsQL™), a validated survey instrument, we measured the parent's perception of the child's quality of life.

We created a demographic questionnaire to measure potential confounders and secondary outcomes such as family size, household income, employed adults, insurance status, caregiver education level, use of community services and number of years in the United States (as a proxy measure for acculturation).

During the study period, the scales were not demonstrating large changes, and we desired more reach data about the groups, we conducted qualitative semi-structured interviews to better understand the components of the program. Qualitative data were collected via open-ended questions allowing the parents to tell us what things are working and where the groups could improve. Questions varied depending on the number of NEFF groups the individual had attended. Questions probed recruitment and enrollment, reasons for attending or not, group topics, and the overall support systems. Phone interviews were recorded and transcribed in Spanish, coded and analyzed using qualitative thematic network analysis to identify themes. Discrepancies were discussed and consensus reached.

#### RESULTS/OUTCOMES (ANTICIPATED/UNANTICIPATED):

Over the grant period, *Niños Especiales/Familias Fuertes* had 731 contacts with Latino parents with children with special health care needs (CSHCN). We conducted the social support and empowerment groups three to five times a month. By alternating times of day and days of week, we maximized the number of participants. We also offered incentives for participation in the

form of a drawing for a gift card. The Spanish-speaking *promotoras* called families and told them about the monthly schedule, and we hung signs about the groups in each of the clinic's exam rooms. Initially, we sent reminders to the home addresses, but these were not very efficacious, as people moved and misplaced the flyers.

Throughout the grant period transportation was a major issue for our families. Especially as the economic crisis increased, families had less to spend on transportation. We had some families that helped others to make it to meetings. We also had a period of time in which we were able to offer transportation through Holy Cross Ministries. Unfortunately, none of these options provided sustainable solutions to the issue.

Child care during the groups was vitally important to the success. With the grant funding, we were able to provide child care during the groups so that parents could focus on the classes. The child care groups contained both children with and without special needs.

In addition, to meet some of the medical goals of our program, we ensured that families were notified that influenza vaccine was available and the county immunization nurses were available to register families and provide vaccine to them at most classes. At baseline, our clinic had a very high rate of immunization coverage for all children (>90%), therefore we did not compare rates between those who did and did not participate in *Niños Especiales/Familias Fuertes*. We did look at influenza immunization rates, and families who participated in the groups had a

slightly higher immunization rate than those who did not participate. We had specific topics on the care of children with Down syndrome, so that families would be reminded to schedule the recommended periodic services.

More formally, we looked at families with and without CSHCN to understand the population at baseline. Both groups were low socio-economic status and primarily Mexican. Education, employment, country of origin, and age were similar between the groups.

Using the Social Capital Scale (SCS) we surveyed 90 parents with CSHCN and 93 parents without CSHCN. Parents with CSHCN and parents without CSHCN had similar scores on the Total SCS and the SCS subscales. Both populations had the lowest scores in “informing and asking”.

Table Two:

Results from SCS			
Subscale	Mean CSHCN	Mean Non-CSHCN	Mean Difference (95% CI)
Total SCS	65.0	66.2	-1.2 (-4.0, 1.6)
Total (weighted) SCS	16.3	16.4	-0.1 (-0.8, 0.6)
Common Good	3.4	3.5	-0.1 (-0.3, 0.1)
Sense of Belonging	3.1	3.2	-0.1 (-0.3, 0.1)
Spiritual/Community	3.2	3.3	-0.1 (-0.3, 0.2)
School Connection	3.7	3.6	0.2 (-0.1, 0.4)
Inform & Asking	2.8	2.6	0.2 (-0.5, 0.4)

Total (weighted) SCS range from 5 to 25 and subscales range from 1 to 5.

Spanish-speaking parents with and without a CSHCN did not differ in social capital, yet were on

the lower end of the standard mean result for the SCS. Our findings suggest that low income Latino families with a CSHCN are just as connected to their community as other low income Latino families.

Parenting children with special health care needs (CSHCN) is associated with poor emotional and physical health in parents. There is little published data about parent health in Spanish-speaking populations with CSHCN. We compared the results in our population and found the following:

Table Three:

Significant Results of SF12v2			
Domain	Mean CSHCN	Mean Non-CSHCN	Mean Difference (95% CI)
Role - Physical	48.0	52.3	-4.4 (-7.4, -1.3)
Mental composite	44.7	50.4	-5.7 (-10.0, -1.4)
Social Functioning	44.9	50.3	-5.4 (-9.2, -1.6)
Role - Emotional	41.9	47.9	-6.0 (-10.3, -1.7)

Spanish speaking parents of CSHCN have poorer mental health and social functioning than parents without CSHCN. They report more role limitations due to physical health and emotional problems. Programs targeted at improving the mental health of parents with CSHCN might raise these critical functions to the same levels as parents without CSHCN

Our qualitative analysis, after interviewing 25 families, revealed no major differences between families who have participated and those who have not. Dominant themes that emerged about barriers to participation included poor dissemination of information regarding the groups, trouble

balancing work schedules, the needs of other children, and lack of transportation to the clinic. All participants agreed that what was being taught in the groups and what was being learned in groups is beneficial to them and their families. Many desired sessions addressing disease specific issues, behavioral conduct of children, nutrition, parenting issues, speech therapy, development, and communication.

#### PUBLICATIONS/PRODUCTS:

The Project Director submitted and presented abstracts at local and national pediatric meetings. These pediatric meetings are for academic and community pediatricians.

Hobson WL, Donaldson AE, Caplin DA, Hobbs AW, Buchi, KF. (2008) Does Having a Child with Special Health Care Needs Decrease Physical and Emotional Health in Spanish-Speaking Parents?

Pediatric Academic Societies, National Meeting, Honolulu, HI. May 5, 2008.

Hobson WL, Donaldson AE, Hobbs AW, Valenti, C, Buchi, KF (2009) Does Having a Child with Special Health Care Needs Affect Social Capital in Spanish-Speaking Parents?

Pediatric Academic Societies, National Meeting, Baltimore, Maryland. 2009.

Schmidt JW, Buchi KF, Hobson WL (2010) Qualitative Evaluation of the *Niños Especiales/ Familias Fuertes* (Special Children/Strong Families) Support Groups.

Academic Pediatric Association Advocacy Training/Serving the Underserved Special Interest Group meeting, Pediatrics Academic Societies Meeting, Vancouver, Canada, May 2010.

University of Utah Medical Student Symposia, Deer Valley, Utah, Fall 2009.

For the research that was conducted, surveys were created for important demographic information. In addition, a question guide for a semi-structured interview was developed. A research database was maintained using Microsoft Access and Microsoft Excel. We plan to

submit at least two manuscripts for publication for our work with *Niños Especiales/ Familias Fuertes*. We will target the following publications: Journal of Healthcare of the Poor and Underserved; Contemporary Pediatrics; Consultant for Pediatricians; Journal of Children and Poverty, Health & Social Work; Progress in Community Health Partnerships: Research, Education, and Action; Journal of Community Health and Journal of Immigrant and Minority Health.

A separate participant and topic database was maintained using Microsoft Excel. Many of the sessions, especially those with guest lecturers have a PowerPoint presentation and handouts. Each session was videotaped and a DVD recording was created. The educational topics include: Genetics, Behavioral management, Legal guardianship, Sign language, Autism, Down syndrome, Speech therapy, Hearing testing, Immunizations, Immigration, and Disaster prevention and preparation.

#### DISSEMINATION/UTILIZATION OF RESULTS:

The *Niños Especiales/ Familias Fuertes* project team has worked diligently to disseminate the program, products and research findings with others. As described above, we have presented the research results in a variety of local, regional and national settings. We have also given oral presentations about the project, as described below:

Hobson WL. (2007) *Ninos Especiales/ Familias Fuertes* (Special Children/ Strong Families): Empowering Latino Families with Children with Special Health Care Needs. American Academy of Pediatrics: Community Pediatrics, The Medical Home and Beyond, Orlando, Florida, June 29, 2007.

University of Utah Department of Pediatrics Combined Noon Conference/ Research in Progress on March 11, 2008.

Hobson WL. (2008) *Ninos Especiales/Familias Fuertes (Special Children/Strong Families): Empowering Latino Families with Children with Special Health Care Needs*. American Academy of Pediatrics: CATCH and Healthy Tomorrows Training Meeting, Chicago, Illinois. August, 2008.

We are still planning on sharing the DVD resources with others in Utah, via Utah Family Voices and the Medical Home Collaborative Project. In addition we will be a part of the Healthy Tomorrows Partnership for Children video-taping at an upcoming meeting in July 2011.

#### SUSTAINABILITY:

We intend to continue the activities of *Niños Especiales/ Familias Fuertes* for the foreseeable future.

Throughout our five year project, sustainability of the program has been a focus. We designed our partnerships so that sustainability of the program would be guaranteed. Our partnership with Holy Cross Ministries is the key collaboration that will lead to continued programming. Holy Cross Ministries has committed to continuing the support of the *promotoras* to the program. We have also found support for the *promotoras* through the Children's Healthcare Improvement Collaboration (CHIC), a CHIPRA Medical Home Demonstration Grant of which we are a participating site.

Our collaboration with the Utah Regional Leadership Education in Neuro-developmental

Disabilities (URLEND) program, a federally funded program to train health professionals to care for children with neuro-disabilities, will also continue past the project time. In a mutually beneficial partnership, URLEND trainees develop and present modules to our groups from September – April. The URLEND trainees have a wealth of knowledge in diverse fields (such as dentistry, physical therapy, nursing, pediatrics, etc). This collaboration guarantees that we have future speakers for the educational sessions.

Utah State University Center for People with Disabilities has been a tremendous partner, which stemmed from our collaboration with URLEND. They have been able to supply the URLEND trainees with content advice, in terms of cultural relevance, translation and interpretation for the groups. They will continue to serve in this role, in addition to providing *Niños Especiales/ Familias Fuertes* with some monetary support.

We will be writing for more grants from local companies to fund the incentives we have for participants. Local stores including Wal-Mart, Target and Smiths Food and Drug will be asked to provide in-kind donations as well as monetary support. Grants will be solicited from Intermountain Select Health as well as Blue Cross Blue Shield of Utah. These grants will be managed through the University of Utah and the University of Utah Development Office.

By continuing the work of *Niños Especiales/ Familias Fuertes*, more Latino families with children with special health care needs will receive the support that they need and deserve. They will learn about the importance of following periodicity schedules for immunizations and for

general healthcare. They will have the opportunity to ask experts about the care of their child, in a comfortable and culturally relevant setting.

## ANNOTATION

Latino children with special health care needs (CSHCN) may not receive appropriate health care because their parents have difficulty understanding and accessing health services due to language, economic or cultural barriers and a lack of social support. By definition, CSHCN require more medical care than other children, and they, therefore, require more care from their parents and other family members. For their children to receive appropriate health care, parents of CSHCN must learn to navigate a complex health care system and frequently must advocate against a seemingly unresponsive system for their special needs child to receive necessary services. *Niños Especiales/ Familias Fuertes*, a partnership of a community-based health clinic and a faith-based community organization engaged Spanish-speaking families with CSHCN in family advocacy and support groups to provide them with the knowledge and skills to obtain appropriate health care for their children. These families thought the groups were valuable, felt supported and learned constructiv information.

## KEY WORDS

Children with special health care needs, Children with disabilities, Family support, Support groups, Latino/Hispanic populations, Health Disparities

## REFERENCES

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## ABSTRACT OF FINAL REPORT

### 1. PURPOSE OF PROJECT AND RELATIONSHIP TO SSA TITLE V MATERNAL AND CHILD HEALTH (MCH) PROGRAMS:

Latino children with special health care needs (CSHCN) may not receive appropriate health care because their parents have difficulty understanding and accessing health services due to language, economic or cultural barriers, and a lack of social support. For their children to receive appropriate health care, parents of CSHCN must learn to navigate a complex health care system and frequently must advocate against a seemingly unresponsive system for their special needs child to receive necessary services. *Niños Especiales/Familias Fuertes*, a partnership of a community-based health clinic and a faith-based community organization engaged Spanish-speaking families with CSHCN in family advocacy and support groups to provide families with the knowledge and skills to obtain appropriate health care for their children.

Collaboration with the Utah State Title V program and the Utah Chapter of the American Academy of Pediatrics (UAAP) has been very important in the success of *Niños Especiales/Familias Fuertes*. Members of both organizations are on our advisory board. We have partnered with a resident who received a CATCH (Community Access to Child Health) grant from the American Academy of Pediatrics and with the Utah Regional Leadership Education in Neuro-developmental Disabilities (URLEND) program, a federally funded program to train health professionals to care for children with neuro-disabilities.

### 2. GOALS AND OBJECTIVES:

**Goal 1:** Increase the knowledge of health care needs and resources, advocacy skills, social

capital and well being of families of Latino CSHCN.

**Objective 1:** Develop a preventive health curriculum for families based on the general and CSHCN specific (e.g., Down syndrome) AAP health care guidelines.

**Objective 2:** Develop a family health advocacy curriculum for families of Latino CSHCN.

**Objective 3:** Implement family advocacy groups for 120 Spanish-speaking families with CSHCN.

**Goal 2:** Measure the impact of *Niños Especiales/Familias Fuertes*.

**Objective 1:** Determine baseline adherence to AAP guidelines for preventive services and immunization rates of participating Latino CSHCN.

**Objective 2:** Determine baseline social capital and parental well being using the Social Capital Scale for families raising children with chronic health conditions (SCS) and Medical Outcomes Study Short Form (SF-12v2™) respectively.

**Objective 3:** Compare the guideline adherence measures, immunization rates, SCS and SF-12v2™ scores following participation in the family advocacy groups.

### 3. METHODOLOGY:

*Niños Especiales/ Familias Fuertes* created the first family advocacy and support groups specifically for Spanish-speaking children with special health care needs (CSHCN) and their families in Salt Lake County. The project is a collaborative effort between a community health clinic, the South Main Clinic and a faith-based community organization, Holy Cross Ministries. After obtaining ideas and input from families, we created a series of groups that would gather at the clinic at various times of the day to discuss issues relating to raising CSHCN. To make the program low cost and sustainable, we partnered with local organizations to provide the teaching for the groups. We used donated space in our clinic. We found volunteer or low cost child care providers. Other local businesses provided donated food for the groups. The groups met at an

average of three times per month. Some families participated in all sessions, some in only one.

4. EVALUATION: We performed both qualitative and quantitative study of the outcomes of our groups. The qualitative study was conducted as semi-structured interviews and the quantitative study as surveys of health and wellbeing, social capital and pediatric quality of life.

5. RESULTS/OUTCOMES (ANTICIPATED/UNANTICIPATED): Over the grant period, *Niños Especiales/Familias Fuertes* had 731 contacts with Latino parents with children with special health care needs (CSHCN). We conducted the social support and empowerment groups three to five times a month. In addition, to meet some of the medical goals of our program, we ensured that families were notified that influenza vaccine was available. We had specific topics on the care of children with Down syndrome, so that families would be reminded to schedule the recommended periodic services.

Throughout the grant period transportation was a major issue for our families. Especially as the economic crisis increased, families had less to spend on transportation. We had some families that helped others to make it to meetings. We also had a period of time in which we were able to offer transportation through Holy Cross Ministries. Child care during the groups was vitally important to the success.

We evaluated the *Niños Especiales/ Familias Fuertes* by looking at changes in social capital, health and well-being of the parents and pediatric quality of life. We found little change in the objective surveys so we conducted a qualitative study and learned families valued the groups.

6. PUBLICATIONS/PRODUCTS: The Project Director submitted and presented abstracts at local and national pediatric meetings including the Pediatric Academic Societies meetings in

Honolulu, Baltimore and Vancouver. For the research that was conducted, surveys were created for important demographic information and a question guide for a semi-structured interview was developed. A research database, participant and topic database were maintained using Microsoft Access and Microsoft Excel. Many of the sessions have a PowerPoint presentation and handouts. Each session was videotaped and a DVD recording was created.

7. DISSEMINATION/UTILIZATION OF RESULTS: The *Niños Especiales/ Familias Fuertes* project team has worked diligently to disseminate the program, products and research findings with others. We will share the DVD resources with others in Utah, via Utah Family Voices and the Medical Home Collaborative Project. In addition we will be a part of the Healthy Tomorrows Partnership for Children video-taping at an upcoming meeting in July 2011.

8. SUSTAINABILITY: Throughout our five year project, sustainability of the program has been a focus. We designed our partnerships so that sustainability of the program would be guaranteed; Holy Cross Ministries has committed to continuing the support of the *promotoras* to the program. We have formed collaborations with the Children's Healthcare Improvement Collaboration (CHIC), the Utah Regional Leadership Education in Neuro-developmental Disabilities (URLEND) program, Utah State University Center for People with Disabilities and our parents. We will write grants from local companies to fund participant incentives and other ongoing costs.