

# Family Stories and Pictures

## The Impact of the Culturally Competent Outreach and Support Project



## Digna's Story

My name is Digna Corcino; I'm a mother of a 6yr old little girl.  
Her name is Nangeli and she is a special needs child with various health complications.  
Nangeli is deaf and blind, she also has a serious heart condition.  
SPAN & DBFACES have been god sent. I'll never forget that June day in 2006 when we met.  
I'm very grateful for all my family has gained since that first meeting.

The support, the guidance and the hope is priceless.  
I cannot express with words what it means to my family and me.  
Gratitude is not a good enough word to express it, I wish I knew of a better word.  
Before I met these wonderful people, I felt like my family and I were swimming  
in an abyss, deep in the sea with no sense of direction or hope.  
Thank GOD that now I'm doing much better and so is my child.  
Sometimes during conferences, I felt like the words were stabbing me in the heart. I cried non-  
stop.  
Learning all the things that were out there hurt me because I had no knowledge before that they  
existed.

I did not know how to help my child before. I thought I could never live a life  
not even close to normal. I saw no hope for the future.  
I am eternally grateful and words can't describe it.  
Mercedes & Maria have been to me more than acquaintances, I see them like sisters.  
Thank you for not judging me when you came to my home,  
Thank you for understanding the family's circumstances,  
Thank you for creating learning opportunities and transporting me there.  
Thank you for lending me your voice because I do not speak the language.

I cannot believe that my husband & I learned to have a little fun with our daughter.  
We're still in shock to have discovered that our daughter loves to play and swim.  
We had never attempted tried it before and we were afraid.  
Their help we received was empowering, now we know how to use  
The support and resources to advocate my daughter's education,  
With medical doctors, recreational activities and hope for this journey.  
I have been motivated to learn sign language and teach other family members.  
Upon visiting conferences of Deaf & Blind children, I have been inspired to learn.  
My husband and I carry the Spanish books like a bible. Language was and still is a huge barrier.  
My husband and I have learned how to celebrate our child.  
We now know how to advocate for her and defend her.  
The hope and the supports that my family have received are priceless.  
I NO longer feel alone, after meeting these incredible women from DB FACES & SPAN and these  
Amazing other parents of special needs children, I know that we're going to be okay.  
My hair has grown, my body aches got better and I no longer eat my nails,  
Instead I read, I am learning English and I continue to learn about my daughter's health issues.  
I never thought that I would meet people, who spoke my language,  
People who understood my family's situations and people who could show me how  
to navigate a complicated system that makes you feel like you're in a maze.  
I feel like I've found family and now I know which way to go.

Meeting other parents of children who are deaf & blind has been very inspiring and I feel supported and grateful.

**For the first time since my child was born, I have felt some happiness and I feel like GOD didn't abandon me.**

My thanks to Diana from SPAN for her generosity and support of this great project. Your contribution and resources to this program was life changing.

Cindy from DB FACES, I am still enjoying the sign language lessons and I will never forget your kindness and all you taught me about deaf & blindness. The new parents I met, thank you for checking up on me once in a while. Yolanda, you are truly an angel.

Blessings and my love to all,

Sincerely,  
Digna Corcino

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## Home Visit to Jovita's Home

Submitted by Myriam Alizo,

I just arrived home after our home visit at Jovita's. We spent there almost 3 1/2 hours. It went pretty well but we could clearly identify 4 barriers that this family is facing:

- Language
- Disability
- Poverty
- Cultural

Jovita and her family (5 children) live in a second floor apartment. She needs to carry the wheel chair for Emilyn up and down the stairs every time they leave their home. There are no elevators, and it has been very hard for them to move to a first floor apartment: these apartments (first floor) are very limited and unaffordable for them. Cindy and I talked about Section 8, and while we were there I made a phone call, but then we had to face the reality that all applicants need to have a legal status. The adults in this family don't have it. We explained to the agency that one of the children in the family had a significant disability, but apparently it doesn't matter. Cindy is going to find out if perhaps through their "parent consultant" (DB FACES) they can identify an agency that could help them with housing problem and we will try to find an agency that can help with housing for undocumented immigrants.

Jovita expressed that she needed to improve her level of communication with her daughter. Cindy will contact the Commission for the Blind to request equipment for Emilyn to use at home (and at school, if it applies). Cindy will go to Emilyn's school to observe what the school is doing in terms of communication, and then she will work with the family at home. Jovita will deliver a letter to the school and the district requesting Cindy to be invited to all educational meetings regarding Emilyn. Cindy mentioned that Mercedes and Maria are working on the standard letter for this purpose.

It was a very touching experience for me to be part of this home visit today.

## **A word from Vivian**

Seven years ago my life turned round 360 degrees. I had my son, Hans, who had a brain hemorrhage. I thought: my world is over!! I asked myself thousands of times, why me, God? What did I do wrong?

I was often depressed without knowing that I was going through depression stages; because of that I didn't visit the doctor, even less was I in the mood to attend a support group, until one day I was invited to a SPAN meeting. There I discovered that I wasn't alone, that I wasn't the only one that has gone through all this.

I met a family ready to help me and to teach me how to fight for my son.

Nowadays I thank God for having met them all, and for the patience they have had guiding me and teaching me because I don't speak English, and this is one of the greatest obstacles in advocating for Hans. I mention this because not long ago, in June 2007, I felt frustrated with my son's school because of the lack of certain services that might help him progress. As soon as I told Mercedes Rosa, Cindy R. and Maria Teresa, they responded right away, to the point that the day we had the IEP meeting they were there and they helped me advocate for services that Hans needed.

This year, Hans is learning a lot, and I am happy and in peace knowing that he is getting everything he needs.

Now, I am a different person, with more knowledge and I am optimistic in this struggle with my child.

Thanks for being around and I hope other mothers would benefit as much as I have.

Vivian Baza

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## **Parent Testimonial: Nilda Maldonado**

When I first received the letter from SPAN, talking about the organizations that could help, the different topics, I was excited. I did have some knowledge about what DDD [Division of Developmental Disabilities] could do, other different organizations, but I realized that many parents had no idea about organizations that could help them or their children, even in school. Most of the parents had children in school many years already and didn't even know about DDD. They were not aware of anything, they just closed themselves. Their child has a disability, they believe the school is going to provide what their child needs, but they don't know how to go around and search for different resources.

That first meeting helped a lot of parents, even me! Even though I already knew about DDD, and the Catastrophic Illness in Children Relief Fund, I didn't know about DB FACES, that was new even for me. As a Latina mother, I believe that Latino families often need to be guided, taken by the hand to do something; it's really hard to just go and look for something; we are always afraid that

something is going to go wrong. One of the questions at the focus group was, do you believe that any professional is always right, the parents all said yes, that's how they were educated in their country, they don't realize anybody could make a mistake!

Most of the parents were having a lot of problems with their children's vision and hearing impairments. They didn't really know what was in their child's IEP because it was in English! They weren't aware of whether or not their children were even getting the services. Most of the parents had never gone to the school because of the language barrier. They didn't know that the IEP should be in Spanish so they could understand it. They always sign everything without knowing what they are signing because they didn't know that they had rights.

At that first meeting, the parents were happy to meet other Spanish speaking parents; even now, how excited they are to talk about their own children; they never used to talk about their children. They used to say "We have family problems" and kept everything inside. Now they have support from other parents, it's given them hope! Even if their children don't have exactly the same conditions, they get support from each other, they feel more free to ask for something because they know it's possible. Before they closed themselves within the four walls, they didn't realize that there were other Spanish speaking parents outside those walls with children with the same disability of deaf-blindness, and even that there were other families whose children had even worse conditions than theirs.

For parents to know they were going to get reimbursed to come to the focus group and the follow-up meetings, they were excited, it really encouraged them to attend. With children who have the conditions of our children, it's not easy to find a babysitter, to find someone you trust. I couldn't just leave my child with the oldest one in the house and go to a meeting; with her disabilities, it really has to be a responsible person to take care of her. Knowing that I can pay for the babysitter makes me feel more comfortable during the meeting. There were parents there at that first meeting who had never left their child with anyone! Even me, being part of this project, this is the first time I've ever left my child overnight in 16 years!

The weekly follow up, ongoing talking to the families, this is really helping us all a lot. Some of the parents just want to get things out that they can't get out with other people. As a part of the project, I feel so happy that they feel comfortable telling me how they feel, when they are stressed, how can they solve problems, how their children are doing. I try to give help when I can, and connect them with organization that can help them, to relieve the stress. In our situation, there is always a stress there, there is always something on your mind, and it's not easy to communicate about it.

In school, the parents are not really aware of the extent of their child's visual or hearing impairments. No one from the school helped them understand that whatever is going on at the school should be followed up at home. The schools don't share what they are doing at school and the parents don't share what at they are doing at home. This really interferes with the children's progress. The project has helped to involve more of the parents in their children's school and let the schools know that they must provide someone at the meeting to translate for the parents. Parents are beginning to lose that fear they have that there won't be anyone there who can speak Spanish, or that they don't have a right to ask for something for their child. The project has helped prepare the parents for when they go to their child's school, even if they have to write down

everything they want to say and do. The project has offered trainings for the parents in how to communicate with the schools.

The project hasn't just helped us with teachers but with other service providers, even doctors. Medical is one of the biggest issues, especially for children who are blind, it's really hard to find a doctor, the type of lens that they provide to the children, thick lens, that's the only thing the government will provide for them. And sometimes it's hard for us to find doctors and ophthalmologists, because not everyone will take children that have disabilities. Plus we face the language barriers; there is no way to explain what we are looking for, what our children's needs are, how to deal with our children.

At the SPAN conference, the parents I took with me learned so much! They really got a lot out of it. Even I learned something! I always keep everything for my child but I never really organized it. The day after the conference, I bought folders, put everything in the folders, this has really made my life so much easier! Another parent was so happy, she didn't know that the IEPs and the IEP meetings should be in Spanish. And just being able to have a day away from home is important, because so often they don't have any respite from taking care of their child.

The DB FACES presentation was excellent. Before that day, none of the parents knew that someone from DB FACES could go to the school and visit their children, evaluate their children, see their needs and explain to the teachers how to address those needs; she is going to visit all the children in school, she got the names, and the school they are attending, now her goal is to train the teachers and staff in the classrooms. She is also teaching the parents how to develop better communication with their children and now they are trying to find different resources such as computers. Unfortunately, none of the schools is working with the parents to teach them how to communicate with their children. For many parents, their children only communicate in sign language, but the parents don't know sign language and the school won't teach them sign language.

The families have a lot of hope in us, they are really thankful. There is a big difference from the first meeting to the last meetings we had, in the faces of the families. One parent really stands out for me. The first time I met her the only thing I could see was crying. She kept saying, "There is nothing for me, there is nothing for my daughter, my hands and feet are tied, I can't move, I can't do anything." Now that she knows that things can be better, she has a smile, she has hope, not that the program is going to be able to do magic, but that there is help for them. The parents believe that they and their children deserve and can have a better life, they have better expectations of what they want for their children. Now they know organizations, they know names of people who can help, they know where to go. Before they were lost, they didn't know where to go or what to do, and what we realize is the schools don't provide enough information; they believe that it's not important for the parents or they just don't want to be bothered but the schools aren't providing what the families need. This program has been changing their minds about the future and their lives today.

My participation in this project has really had a positive impact on me. I'm by myself in this country, I don't have any family around. Having these families now makes like a big family when we get together, we can talk about everything, in person, on the phone. We talk like friends, like family. We have that freedom to talk about our children, about different problems. It doesn't feel that your problems are as bad as they used to be because we can share them. It gives us a release on our stress. I feel more comfortable and I realize that I have support. The program is giving us

legal support, to make sure we are getting our rights; before everybody would think you have to pay for legal support. It's making life easier for families with low incomes and language barriers. It's letting everyone know about all the resources that the system really hides. It's great knowing that, even if the children can't communicate, now they have a voice for them because their family is being empowered. Before, no one could talk, everybody was speechless, but now all the children have so many people to talk for them! And we know if we get stuck, there's going to be somebody behind us to help us. That gives us the grounding we need to feel secure to speak on our own behalf and for our children and each other.

Before this project, not only were the children blind and deaf, it was also the parents who were blind and deaf and this project has cured that; the whole family was blind and deaf, they knew nothing, they didn't see anything: THEY NEVER SAW THE SCHOOL, NEVER HEARD ANYTHING FROM SCHOOL ABOUT THEIR CHILD. We are all glad now that they finally opened their eyes start to see, they opened their ears to hear. This was one of my lifelong dreams, that one day I would be able to help Spanish speaking families who have children with disabilities, to help them make their lives easier, to help them get what they need. This project has helped my dreams come true!

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## Update on Nangely

Submitted by Maria Abinader,

Nangely is seeing an eye specialist on July 14th in East Brunswick. According to her mother, Nangeli has not gotten formal evaluations (eye, cardiology or neurologist). Her mother is happy because she got a Saturday appointment so Nangeli won't miss school. (In the past at her regular clinic, she always had to miss school). We just got the appointments this morning, I was her interpreter.

The week of July 23rd Nangeli is seeing the cardiologist.

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We also did a three-way conference call with the insurance company (Horizon Mercy).

Nangely was not registered with the Special Child Health Services Case Management Unit. She will be assigned a case manager.. Nangely's mother is expecting her call. I reminded Nangely's mother to say she speaks Spanish as soon as she calls so that there won't be communications barriers.

Previously we provided the family with instructions on how to apply for food stamps and housing; the family is now receiving food stamps benefits including a reduced phone bill. The family also got a housing application, I helped her fill it out last week. This family is doing better and Nangely's mother is participating more and more.

Next steps: Get Nangely a neurologist evaluation and help with gas & electric.

## **Vivian Baza's IEP Meeting - "What a difference a year makes!"**

Submitted by Mercedes Rosa, Director,

The IEP meeting went really well today. What a difference a year makes! Vivian attended the SPAN Conference and other trainings over the past year that has served to equip her to be a full participant in her child's IEP meeting. For the first time she understood her role and came prepared to speak/collaborate at the meeting. Vivian had organized notes concerning her child's health, progress and behaviors over the past school year. She presented very confidently and clearly expressed her concerns and requests to the team.

### Building Bridges

We had quite a welcoming committee! The district decided to bring their Attorney, Superintendent and the School Psychologist who also serves as the Case manager. I was glad that I knew the Attorney from Union County so things went quite smoothly. The district was quite cooperative and complied with every request.

Vivian first thanked the Principal, therapists, teachers, and staff that work daily with her child and the district for their ongoing commitment. (A little sugar goes a long way!)

### Outcomes of the IEP Meeting

We were able to get a change in the classroom placement for the upcoming school year to a more inclusive placement, a change in related services and supports, a trained one to one aide, and more individual therapies (Speech, occupational and physical therapy). The district honored the request to do a Functional behavior assessment and develop a Positive Behavior Plan. The best part is that they agreed to let Cindy (for NJ DB FACES) be present and participate in the assessment, parent interview and observation. We presented Cindy as the expert that is needed to help develop an effective plan. Services in school and at home were discussed and the specifics will be discussed in greater detail after the FBA is completed. We will meet to develop the PBS the week after the FBA is completed and we will amend the IEP as necessary.

Cindy has made two visits to the school. She provided TA and strategies to defuse the behaviors by giving him increased visuals and tools to increase communication. The behaviors have de-escalated since Cindy's strategies were implemented.

### Materials in Spanish

The PRISE (Parental Rights in Special Education) booklet was not provided in Spanish even though the state has a translated version. The excuse that was provided was that it was an "oversight." A translator came but she was ineffective: she could not keep up and did not translate what was being said... The School Social Worker stepped in to provide cohesive and clear translation.

We requested that in the future everything (IEP, Assessments, Progress Reports, Written Notices) be sent in Spanish. We mailed the letter from Diana Autin (SPAN's Executive Co Director and an attorney) to both the Superintendent and Case manager supporting Vivian's request for all correspondence to arrive in Spanish. Vivian is thrilled and I remain on the euphoric high I get after things go well!