

A Partnership in Providing Support

by Kathy de la Pena, Member-at-Large Southwestern Region

Rosalinda De la Cruz remembers vividly the day her son, Geneito, was born. "They told me someone would come to talk to me. I waited all day, and no one ever came. I was afraid, and it was difficult for me to accept that he had Down Syndrome. I just needed to talk to someone." Several months later, Geneito was enrolled in an Early Childhood Intervention (ECI) program, and Rosalinda told the story of her son's birth to Yolanda Rios, the home visitor from the program. Rosalinda thought that there must be other parents who felt the shock and despair that she had at first, and she longed to hear their stories and help them if she could. She asked if Yolanda would help her get in contact with them. Yolanda agreed and a *partnership* was born.

The two women, parent and social worker, began to brainstorm ways of bringing families together. The program's home-based early intervention model was effectively addressing individual concerns within each family's daily routines, but it allowed little opportunity for families to come together. Yolanda was aware of several other families who were enrolled in the ECI program whose children had Down Syndrome, and she agreed to ask them if they were interested in getting together with other parents. Several of the parents showed an interest and one volunteered her home for the first meeting. A flyer announcing the date and time was mailed out from the ECI program.

Only three mothers showed up for that first meeting, but an instant bond was formed and they were eager to share their stories. "No one else, except another parent, can understand exactly what it is like to have a child with Down Syndrome," Rosalinda is quick to say. "I was so happy to make contact with other families right here in my own community."

The parent group has changed considerably from that first meeting. Now, on average, 12 adults gather once each month to listen and support each other. Sometimes the families meet to listen to a speaker, other times they work on a project. Recently they put together scrapbook portfolios about their children. The portfolios will be shared with extended family members and presented to their school districts upon transition from the ECI program. Mainly the meetings offer a place where parents with similar concerns feel comfortable comparing notes, sharing resources, and learning from each other's experiences. They provide a nonjudgmental environment that supports parents with newborns as well as an open forum for discussing parental concerns about their children's future. The parent meetings have become an avenue for parents to become better informed as they are asked to make difficult decisions regarding their child's social and educational needs.

There are many reasons that the group has been a success, but Yolanda believes that the main reason is that from its inception it has been *parent directed* and *program supported*. The original group met in response to an identified parent need. "We responded to that need and then made sure that the parents continued to guide the group's development. When we meet a challenge, we work together to solve it. Attempts in the past to start a parent support group because professionals thought it was a good idea, had failed. The need has to come from the families we serve. But often times families, don't have the resources to keep a group going. That's where the program can help by providing facilities, childcare, speakers, and postage."

Just recently the group celebrated its two-year anniversary. The regular attendees look forward to the meeting each month. It is a chance to see old friends and meet new ones. It is a break from their demanding daily routine of parenting a toddler with special needs, and with refreshments and babysitting provided, it offers a couple hours of respite. The group has also reaped unexpected results. When working on the portfolios, computers were made available to the families. Some parents were given the opportunity to work on a computer for the first time while others improved their current skill level.

Recently Yolanda visited a doctor's office hoping to ask the pediatrician to be a guest speaker for the parent group, but she became discouraged about getting in to see him when she saw his packed waiting room. One of those waiting was a regular at the parent meetings. She immediately spotted Yolanda and invited her to go into the examining room with her when she and her child were called. This resulted in the doctor wanting to learn more about the group and his agreeing to be a speaker at one of the future meetings. "We were much more convincing as a team," Yolanda reflected later.

The parents attending the group have become closer friends, and there is more socializing between them outside the group. "We invite the other children to our birthday parties, and we share phone numbers so if someone wants to talk between meetings. We make ourselves available," says Rosalinda. The group is now discussing whether or not to invite parents of children with concerns other than Down Syndrome to their meetings. "As it stands right now, anyone is welcome, but we haven't *officially* invited others. At first, I guess, we just wanted to find each other. Now we are ready to open up to a broader circle of friends."

