

A new Parent Leadership Institute is being planned for May 2005. We are seeking states interested in participating. The four-day Institute aims to meet the learning needs of the participants and support the work that groups of parent leaders will do when they leave the Institute to return to their respective states. The Institute will include interactive activities, parent storytelling, and intensive state team planning. Each team will go home with a plan they have developed for moving ahead on parent leadership. Location will be announced once we know where the Institute will be held. ***Contact us for more information.***

Summer Events:

July Topic Call

The National Parent Leadership Development Project for ICCs held a topic call for parents on July 30, 2004. The topic was "Successful Strategies and Materials on Outreach to Hispanic Families." Eight people (representing Nebraska, Georgia, Arizona and Massachusetts) participated on the call. Contact us for ways to connect with the call participants. Also, we encourage you to please send us your ideas for future topic calls. The following is a summary from our July call:

Family Involvement

- We meet with various groups, get our names out in the community (such as the Down Syndrome Connection, made up of Spanish speaking families only)
- We organize meetings for families to meet and network
- We build core groups of families involved in EI or have been out of EI for just a few years
- We serve two counties and one Native American reservation the size of CT with many Spanish-speaking families
- In Omaha we outreach through local ICC, planning region teams; we get info to families and ask them what they need
- Contact with Spanish-speaking families—we meet, give information to families, hear their needs, organize and schedule meetings
- Sometimes it is discouraging when you walk into a meeting and there are only 1 or 2 families there, but it is okay!
- We send out questionnaires to families once a year, asking them what made sense and what didn't
- We send out surveys
- One parent put a resource book together while working at home
- It is important to let families know about the different opportunities and the many ways to get involved
- Children are included, in the back of the same meeting room with someone to care for them while the parents are meeting
- Meetings are held in a Hispanic community so parents can feel comfortable
- Transportation is a big issue for some families, so we provide transportation
- Families feel in control with EI because they know it is safe
- Parents will not call the SSI office; they are afraid of their legal status in the U.S. At this moment, this is a major problem
- Immigration officials drive around neighborhoods asking for driver's licenses; people are scared. We keep telling them that nothing will happen...the services are for their child
- It would be good to have a national conference, where you can connect with families from all over the country. It is so powerful just for families to get together
- We inform families on services that are available to them

Translations

- We have parents read our translations to see if they are meaningful and what they like and dislike about it

- There is a mother originally from Mexico who does great translations with our materials and newsletters and brings it down to an appropriate reading level
- Try to have enough bilingual staff to serve these families
- We have had pretty good luck in one of the communities because of a lady who is always willing to translate whenever we come out
- Letting parents know about PTI and giving them translated materials
- Goal = all presentations translated and given in Spanish
- So much info for parents to absorb, and the best way to get this info is in their native language
- Important to have native speaker read over translations to make sure that they make sense before they are distributed

Networking

- We try to reach families in a number of ways
- Meeting with different Hispanic leaders
- One family connecting with another family is so valuable
- Take advantage of the availability of speakers who do not ask for payment—part of their outreach efforts
- It is helpful to find out who is the right person to talk to

Church, Hospitals

- Sunday afternoon after church is the best time—families are all together
- 30-40 parents with children. It's important to Hispanic families that they attend with their whole family. This is part of their culture and we accommodate as best we can, even if it means talking over crying children
- Through hospitals is one of the most powerful ways to reach families, take advantage of social workers at hospitals
- Hospitals are the most important piece
- Once the doctors see the impact of our job, they are more open and willing to give their time
- Once referred by the hospital, they call the families and provide simple and clear info in Spanish about Down syndrome, health care, etc.
- Have identified with three major hospitals where Hispanic women have their babies

Organizations

- We are having small successes, which can turn into big successes, but no continuous results
- We have just hired two people so that our success will become more continuous
- Invite leaders to an open house - important to know who we are and what we offer so that they can spread the word
- Mentioned only small successes, but need to remember that these individual successes can change a life
- The importance to include the children in the meetings
- They always try and provide childcare
- Utilize child protection/advocacy groups
- We need to be knowledgeable on who can speak for free
- Service coordinators will help with Medicaid and SSI

The National Down Syndrome Congress had its annual convention which took place in Minneapolis, Minnesota, August 20-22, 2004. They offered this to youth, adults, siblings, families and professionals. A presentation was made by Amy and Christina Robison titled "Accessing Drama Opportunities in your Community" It provided an overview of what is drama, what are the benefits of participating and how to find community drama activities at a local community level.

Resources:

Office of Minority Health Resource Center. The Resource Center offers information (e.g., resources, publications, health and links) on health for the underserved. Contact: Office of Minority Health Resource Center, PO Box 37337, Washington, DC 20013. (800) 444-6472. www.omhrc.org

National Adoption Information Clearinghouse. Information and resources related to adoption. Contact: National Adoption Information Clearinghouse, 330 C St. SW, Washington, DC 20447. For more information, call (888)-251-0075, or email naic@calib.com. www.calib.com/naic

Woodbine House, publisher of the special needs collection. Books about special needs for parents, professionals and children; information on new books, highlights and conferences. To order, call (800)-843-7323 Mon-Fri-9-5. Fax orders to (301) 897-5838. Email anytime to info@woodbinehouse.com.

For more information about our project's clearinghouse of resources, please contact Marilyn Gutierrez-Wilson at (800) 493-2338 x 151 or via email: marilyng@fcsn.org.

Check out our website for more details: www.iccparent.org