EXCEPTIONAL CHILDREN’S ASSISTANCE CENTER

As the Family-to-Family Health Information Center in North Carolina, Exceptional Children’s Assistance Center (ECAC) provides information, education, outreach, and support to families with children across the state, from all backgrounds and cultures. Recognizing the shifting demographics of their service state, ECAC hired their first bilingual staff person in 1999 in an effort to better serve Spanish-speaking families. Since that time the organization has strengthened their commitment to support bilingual families, through the hiring of bilingual staff, staff training, improved language access, services, supports and outreach methods. This brief describes the strategies used by ECAC to strengthen outreach to new families and improve their cultural awareness and practices to meet this growing population.

NORTH CAROLINA COMMUNITIES

Nationally, North Carolina is ranked 6th in Hispanic population growth and has the 11th largest Hispanic population in the country. Out of the entire NC population, 10.8% speak a language other than English – Spanish being the most common language (other than English), with less than 1% of others speaking Hindi, French, Chinese, German, and Vietnamese, respectively.

The significant increase in NC’s population over the last several years is attributed to a significant rise in newly arriving immigrants, with a considerable number whose Native language is Spanish and ability to speak English being identified as “less than very well.” In light of these shifting demographics, ECAC has significantly increased their ability to reach Latino communities in North Carolina, primarily by developing greater cultural competency and seeking to hire ethnically and linguistically diverse staff.

This brief provides information on how ECAC exemplifies promising practices that address important elements of providing culturally competent services. Based on feedback collected from a series of focus groups organized by Family Voices National Center for Family/Professional Partnerships, five essential elements have been identified as benchmarks for an organization’s cultural competence and for reaching and serving culturally and ethnically diverse families. Although a community’s needs and desires are often unique and specific, the following are intended to serve as inspiration or a starting point for other organizations seeking to build greater cultural competency and create a more welcoming and accessible environment for their clients and communities.
**ESSENTIAL ELEMENTS:**

**Provision of language access:** ECAC’s three bilingual staff works one-on-one with individual families, providing interpretation service and translating documents on demand. Moreover, these staff members respond to calls from Spanish-speaking families to ECAC and its satellite locations. Other efforts to improve language include:

- Leading topical workshops and presentations in Spanish and English.
- The most popular and requested materials have been translated into Spanish.
- All materials and workshops in development will be available in both English and Spanish.
- The website and automated phone greeting are available in both English and Spanish.
- Simultaneous translation is available for workshops and all advertisements state the availability of interpretation.
- Activities and training are conducted in locations that allow disability access and can accommodate a diverse group including non-native English speakers and the hearing impaired.
- Adapting existing projects like the Parent Training and Information Center (PTI) that are familiar to support agencies and consumers.
- Modified the skills-based *Parents as Collaborative Leaders curriculum* to be meaningful for families with CYSHCN and adapted or translated it to be available in both English and Spanish.

**Office environments support the diversity of families:** To ensure that parents, children, and others of diverse backgrounds feel welcome and comfortable in ECAC and partner offices, the organization has taken several important steps to foster inclusivity, including:

- Conducting regularly scheduled cultural competence workshops for staff, parent volunteers, and professionals to ensure they are prepared to work with diverse families.
- A lending library of resources with nearly 150 books, CDs, DVD in Spanish.
- Racially and ethnically diverse staff whose first language is not English and who have first-hand experience with caring for children with special healthcare needs.
- A toll-free number – often the first point of contact – that is available in Spanish and English.
- Posters and other visual materials representing racial and ethnic diversity have been placed around the office.

**Staff and partnerships reflect diverse populations:** ECAC has made a strong effort to recruit racially, ethnically, and linguistically diverse staff, creating a more welcome office environment. Additional steps taken include:

- Most ECAC staff are family members of children/young adults with special health care needs or disabilities, or individuals with disabilities.
- Partnering with community and faith-based organizations that have experience and expertise working with diverse communities, and with organizations that have expertise working with individuals with disabilities.
- Conducting outreach to promote services through ethnic media and community and faith-based organizations that serve the most underrepresented families.
- Recruiting subcontractors with language, culture, and disability access policies within their organizations.
- Partnering with Latino organizations to provide statewide workshops in Spanish upon request, and disseminate educational information for Latino parents in their native language through exhibits and the Lending Library program.
- Making diversity a core component of ECAC’s organizational culture including a Board of Directors that reflects the diversity of the families served.

**Connecting families to other families with shared experiences & similar backgrounds:** Connecting families to provide peer support and information sharing has always been a core objective of ECAC’s mission. By expanding that objective to their nascent diversity policy, they are improving the chances of success for parent-provider relations. Steps to build a strong network include:

- Focusing on geographic regions with large populations of ethnically diverse families.
- Outreach programs to identify the most effective leaders in Latino organizations for potential partnerships.
Participating in Hispanic cultural and community events to raise awareness of ECAC services and opportunity.

**Providing opportunities for diverse families to share their opinions and feedback:** ECAC has created an environment that encourages and supports feedback and opinions about how to improve services and supports to diverse families. Through years of feedback and evaluation from families, ECAC has improved services and, most importantly, family outcomes. The following are some of the ways that ECAC has collected feedback and altered supports to be most effective:

- Materials are piloted with diverse families to ensure readability and usefulness and revised based on parent feedback.
- Diverse families and professionals are asked how they can most easily and effectively access services; services are structured to meet those expressed needs.
- Focus groups are facilitated with diverse families to obtain input and recommendations regarding strategies to ensure that ECAC’s activities meet the needs of the full range of NC families. These focus groups reach participants who speak languages other than English, are racially or ethnically diverse, or who have disabilities themselves.
- Participation of families and professionals who participate in ECAC services are continually monitored to ensure that participants reflect the full diversity of NC. The impact of services is monitored using information collected through surveys, evaluations, and interviews.

**CONSUMER RESPONSE:**

“Because staff represent diversity across disabilities and cultures, we approached our work as ‘here’s the problem; how do we solve the issue?’ We worked with families and used interpreters who taught us how to work with interpreters. We work to make it work.”

“Listening to others has changed our culture. We grew into this because we were focused at the family level; it wasn’t imposed on us. We never assumed we couldn’t serve the families who call us.”

“When we are invited into a community, once we are in the room, our biggest teaching tool is the network in that room that has the power to change things on the local level. The staff will come and go but the people in the room will continue to be part of that community and will serve as change agents.”

“We ask ourselves, ‘Are we serving families the way they deserve to be served? Is the proposed change or resource going to serve the families who asked for it?’”

**STEPS FOR SUCCESS**

- Ensure that staff, Board of Directors, and volunteers reflect the racial, ethnic, and linguistic diversity of the communities served.
- Use cultural brokers to help reach and engage underserved ethnically diverse families; use cultural brokers for outreach within the community to learn the needs of that community.
- Find and partner with organizations within the community that have experience and expertise working within that community.
- Rely on the strength and expertise within communities to reach and serve diverse families effectively.
- Put aside preconceived notions and listen to what the families say they need.

**WHAT FAMILIES SAY:**

“One day I was invited to an ECAC meeting. The subject was “Parents as Leaders”. I still remember my fear, my incredulity, and the heavy burden that I was carrying since in the previous days we received the formal diagnosis of Autism for my son. [...] The information received during those three days of training awoke something inside me: the fear I had, started to vanish. Little by little I
got the information needed and learned about my rights and the rights of my child. I want to tell you something that I won’t forget: That day I got empowered, you motivated me and I was able to align my goals.” - Isaura Hernández, Parent

“... I’m the mother of a child with special needs. I’m one of the mothers who have benefitted from the ECAC’s programs. ECAC is an organization which has the purpose of guiding parents of children with special needs, parents like me. ECAC helps us to understand the process of an individualized program and guide us in every daily step we take as parents of children with special needs. ECAC provides us with the orientation that our kids’ school doesn’t give us. Today I want to thank every single person who makes possible that this organization exists. I specially want to thank Ms. Peña who guides us regarding the steps we take in this difficult process. Thanks to Ms. Peña who guides us in our native language. The guidance that this organization gives us is very important because it makes us feel that we are not alone among all the problems we face. Thank you for being the light for us among so many problems.” - Janeth Marino Hernández, Parent

“When we were going through difficult moments with my son, your center gave us sincere and exact help.” Louis Krumeich, Parent