



HEARTLAND
GENETICS SERVICES
COLLABORATIVE

Hispanic Access Project

Presented by Mary Ann Coffman MS, CGC

Heartland's Questions

- ▶ What are the barriers to accessing genetic services?
- ▶ What can genetic service providers do to provide culturally competent quality care for Hispanic patients?

How do we begin to answer these two questions?

- ▶ Qualitative research project
- ▶ Conduct 26 interviews in Spanish (OK., NE., KS.)
- ▶ Caregivers of children
- ▶ Interviews were recorded, transcribed and analyzed in Spanish

Heartland's Team Members

Mary Ann Coffman, MS, CGC

Gene Hallford, PhD


Alexandra Obregon -Tito, PhD, MSC, MA, CGC

Anayeli Herrera Morales, MPH

Lori Williamson Dean MS, CGC

Recognition

- ▶ Families
- ▶ Family to Family
- ▶ Health Professionals (community)
- ▶ Heartland (HRSA)
- ▶ Hispanic Access Advisory Committee



Results and Recommendations

What are the barriers to accessing genetic care?

1. Genetic Services
2. Families perception of Genetic Services
3. Information Delivery
4. Families Expectations of Medical Care
5. Language barrier and translation Service
6. Outreach
7. Cultural Barriers

What is working? (Bridge)

Community

- ▶ Many Hispanic families live in the same communities
- ▶ Community clinics (bilingual staff)
- ▶ Family to Family
- ▶ Home visiting programs (Early Intervention)
- ▶ Social networks
- ▶ Support groups

Recommendations

The slide features a white background with the word "Recommendations" in a large, dark grey, sans-serif font. On the right side, there is a decorative graphic consisting of several overlapping, semi-transparent green shapes in various shades, ranging from light lime green to dark forest green. These shapes are angular and layered, creating a modern, abstract design.

Recommendations

1. Create a regional Hispanic Access Advisory Committee and form partnerships with healthcare providers, educators, early intervention staff, community leaders, family networks (etc.) to develop an interdisciplinary system capable of meeting the needs of Hispanic families with genetic conditions.
2. Develop and provide comprehensive and appropriate education and information relating to genetics and genetic services, for healthcare providers, early intervention programs, family networks, community leaders and Hispanic families with genetic conditions, to meet the patient's healthcare needs.

Recommendations (cont.)

3. Increase awareness about genetic conditions and services to the Hispanic community including parent support agencies and groups with the purpose of increasing interest/acceptance within the community.
4. Explore the cultural and religious beliefs identified in the Hispanic population that may influence the parents' understanding and acceptance of their child's genetic condition.
5. Develop a more programmatic approach to overcome communication barriers experienced by non-English fluent families.

Recommendations (cont.)

6. Share information with other agencies and committees on the need to educate Hispanic families on the American health care system.
7. Increase awareness among genetic service providers and staff about cultural beliefs and practices.
8. Establish partnerships among genetic service providers, community based health care systems staff and parent support groups for families with CSHCN.

Hispanic Access Advisory Committee (HAAC)

Members

Jennifer Roberts, MS, CGC (KS)
Carmen Paniagua, EdD, MSN, FANNP (AR)
Lindsey Mette, MS, MScPH, CGC (TX)
Erica Herrera (OK)
Heather Smith, MPH (KS)
Genoveva Fernandez (KS)
Howard Smith (MO)
Claire Mente (Genetic Alliance)
Janet Thomas, MD (MSGRC)
Margarita Sifuentes Saenz MD (MSGRC)

Marilyn Brown, MPH (MSGRC)
Graciela Sharif (NE)
Milagros Garcia (NE)

Ex-Officio Members

Klaas Wierenga, MD
Gene Hallford, PhD
Anayeli Herrera Morales, MPH
Mary Ann Coffman, MS, CGC
Lori Williamson MS, CGC

HAAC

- First in Person meeting on May 4, 2016
- Four teleconference calls

Top three recommendations selected by HAAC

2. Develop and provide comprehensive and appropriate education and information relating to genetics and genetic services, for healthcare providers, early intervention programs, family networks, community leaders and Hispanic families with genetic conditions, to meet the patient's healthcare needs.

(Education)

5. Develop a more programmatic approach to overcome communication barriers experienced by non-English fluent families **(Policy)**

8. Establish partnerships among genetic service providers, community based health care systems staff and parent support groups for families with CSHCN.

(Community Partnerships)

Discussion points as HAAC addressed the top recommendations

- ▶ Families perspective
- ▶ Genetic Service provider perspective
- ▶ HAAC'S discussion points
 - Education at all levels
 - Community partnerships (promotores)

Reginal Genetic Networks (RGNs) for FY 2017


Purpose:

- I link medically underserved populations (based on poverty, rural geographic location, and/or populations that experience health disparities) to genetic services;
- II implement quality improvement activities to increase the connection with genetic services for the medically underserved;
- III implement evidence-based innovative models of telehealth² and/or telemedicine with a focus on clinical genetics outreach; and
- IV provide resources to genetic service providers, public health officials and families.

National Genetics Education and Family Support Center for FY 2017

Purpose

- 1) improve family engagement for individuals and families who have, or at-risk of having, a genetic condition;
- 2) provide support for such individuals and families;
- 3) provide education and resources on genetic conditions;
and
- 4) link individuals and families to services, especially those in underserved areas.



“Where there is a problem
in one place there is a
solution in another.”

¡Muchas



Gracias!

Questions

