Partnering to Make Services Easier to Use for Latino Families with CYSHCN-PA Experience

Facilitator: Myra Rosen Reynoso

Presenters: Diego Chaves-Gnecco, MD, MPH
Renee Turchi, MD, MPH, FAA
Emilio Pacheco, MHS

March 21, 2012
Today’s Discussion

- SALUD PARA NIÑOS – Diego Chaves-Gnecco
- EPIC-IC Medical Home Initiative – Renee Turchi
- Vision for EQuality, Inc. – Emilio Pacheco
Webinar Learning Objectives

- Increase awareness and knowledge of the ease of use of services for Latino families with CSHCN (in particular, PA)
- Explore how the presenting organizations can serve as a model for other states/organizations
- Examine specific examples of partnerships, activities, and lessons learned to make services easier to use for Latino CSHCN in PA
Latino Families with CSHCN in Pennsylvania

- 59% of Latino families in PA met Outcome 5 (ease of use of community-based services)*

- Difficulties and delays most often cited by Latino parents
  - Waiting lists
  - Eligibility criteria

*National Survey of Children with Special Health Care Needs-2010
www.childhealthdata.org
Providing Health Care for an Invisible Community:

SALUD PARA NIÑOS

Celebrating 10 Years of Services

Diego Chaves-Gnecco, MD, MPH
Program Director
Assistant Professor - Dept. of Pediatrics
University of Pittsburgh
SALUD PARA NIÑOS (Health for the Children)

- Program Aims
- Methods - Program Description
- Results
- Conclusions
- Future Initiatives
SALUD PARA NIÑOS

Program Aims

1. Reduce health disparities
2. Combat social isolation
3. Partner with community agencies
4. Permit systematic data collection
5. Create an ideal environment for developmental screening
Design

- 1st pediatric bilingual/cultural competent clinic in SWPA
- Created 10 year ago as Medical Home for Latino children and families
- Provides traditional primary care services at CHP, Birmingham Clinic & CHP Care Mobile
- Increase prevention and empower community to address its own health
SALUD PARA NIÑOS
CHP Clinic

- Bilingual-bicultural clinic at CHP PCC:
  - Tuesday mornings
  - Thursday evenings
  - Friday mornings

- Staffed by Spanish speaking physicians, nurses, and volunteers
SALUD PARA NIÑOS
Birmingham Clinic

- Pediatric clinic
  - 2nd Saturday of the month
- Partners with SALUD, medical student initiative via Program for Underserved Populations
- Community support
  - University of Pittsburgh
  - Salvation Army support
  - Americorps members
SALUD PARA NIÑOS

CHP Care Mobile

- 40-foot long
- Donated in 2001 by Ronald McDonald House Charities
- Once a month at Birmingham clinic
  - Increase room availability
  - Track medical records
Co-organize community fairs

- Promote healthy habits and ongoing programs
- Distribute health information
- Give presentations about child care and current health topics
SALUD PARA NIÑOS
Community Programs – CPR Classes
Literacy Program
Bilingual-Bicultural Appropriate Health Materials

¡Protégete! ¡Vacúnate!
La vida traer nuevas experiencias, amigas, y en algunos casos, enfermedades.
Las vacunas son la mejor manera para prevenir enfermedades graves.

¡Algunas vacunas previenen hasta el cáncer! La nueva vacuna contra el virus del papiloma humano puede proteger a las chicas contra el cáncer del cuello del útero cuando sean mayores. La vacuna contra la hepatitis B puede prevenir el cáncer de hígado. Y acudir cada año a recibir la vacuna contra el virus de la influenza o gripe.

¡Disfruta la vida! ¡Vacúnate!

Don't Miss Out! Stay healthy.
You are going new places, meeting people, and sometimes coming into contact with new diseases. Get the vaccines you need to stay healthy. And get your flu vaccine every year.

Did you know some vaccines can prevent cancer? The new human papilloma virus vaccine (HPV) can prevent cervical cancer. The hepatitis B vaccine can prevent liver cancer.

Vaccines also prevent measles, mumps, hepatitis A, meningitis, pertussis (whooping cough), rubella, chickenpox, and other diseases.

Check with your doctor or other health care provider to keep your vaccines up-to-date.

Get Immunized!
For more information:

AAP PA Chapter IEP
Spanish Phone Line

412-692-6000 option 8
Latino Car Seat Checks

AAP PA Chapter
TECHS
Results
SALUD PARA NIÑOS
Numbers served

Years

Patients enrolled

0  100  200  300  400  500  600  700  800  900

2004  2005  2006  2007  2008  2009  2010  2011
Results

- 1000 visits/year
- ~ 100 children assisted with obtaining health insurance
- Partner with Consumer Health Coalition
- Several sub-specialty clinics started
Latino Car Seat Checks

- Since summer of 2003
- 16 events planned and organized
- 429 car seats checked
- 210 car seats replaced
- First bilingual-bicultural certified TECH
Latino Car Seat Checks

Crash kills 1, injures 3

By Glenn May
Monday, December 19, 2005
María

**Before**

- 11 year old with Cerebral Palsy, not walking
- No health insurance
- Traveled 2 hours for primary care
- No handicap license plate

**After**

- Health insurance and handicap license plates obtained
- Baclofen pump placed
- Home and school visits by LEND interdisciplinary team
- Now walking and dancing
Martha

Before

- Mother observed seizures in well baby nursery, unable to communicate concern
- 48 hour delay in transferred to NICU
- Found to have a stroke with hemi-paresis

After

- Inpatient/outpatient care coordination provided
- Linguistic and cultural competent care provided
- Referred to Early Intervention
- Weaned from anticonvulsive medication
- Completely recovered motor function
Guadalupe

Before

- 10 year old with Autism
- Mother eager to be advocate for her daughter and for her community
- Unsuccessful attempts to join local advocacy groups

After

- Connected the mother to a training grant for early intervention specialists
- Help to create first advocacy group for Hispanic parents of children with special needs in region
Conclusions

- Need for culturally and linguistically competent health care for Latino children
- No need for new resources or services in most cases
- Most services are in place and just need to be connected and/or adapted
- Prevention pays
Future Initiatives

- Increase access
  - Health insurance
  - Personnel to staff the programs
- Improve systematic data collection
- Increase and improve developmental screening
  - By improving access
  - By improving systematic data collection
- Continue working in prevention & promotion
- Future research initiatives
¡¡Gracias!!
Partnering to Make Services Easier to Use for Latino Families with CYSHCN-PA Experience

Renee Turchi, MD, MPH, FAAP
March 21, 2012
Background

- Medical home is standard of care for all children
- Larger percentage of Latino CYSHCN in PA vs National (2009-10 National Survey CYSHCN)
EPIC-IC Medical Home Initiative

- EPIC-IC’s mission is to enhance the quality of life of CSHCN through recognition and support of families as the central caregiver for their children, effective community-based coordination, enhanced communication, and primary health care.
EPIC IC Medical Home Sites

- Participated in Medical Home implementation
- Has received Medical Home Outreach/Education

There are 97 sites that have participated in implementation (green dots) and 28 sites (yellow dots) that have received education marked on this map dated 1/19/12.

Some pushpins may overlap when sites are in close geographical proximity.
How do practices participate?

- Quality improvement teleconferences
- Fall & Spring Conferences (networking opportunities)
- Education
  - Identification of CYSHCN
  - Parent Partner recruitment and utilization
  - Coding
  - Time Management
  - “Hot topics” like transition, cultural competency, family-centered care, obesity, etc.
- Quality improvement cycles
Cultural Competency Conference

- Planning committee
- National Center for Cultural Competency
- MCHB
- Break out sessions
- Action Plan
- Provider Self Assessment (NCC)
Advocating in Practice

- Ciracom Phones
- Role of Cultural Brokers
- Community Partners
- Resources for families
Autism Conference for Families

- Planning Committee
  - Community Partners
  - (Visions, Families, CAR, CHOP, SCHC, Asert, BAS)

- All presentations in Spanish

- Resource Fair

- Reverse Translation
POR FAVOR UNASE A NOSOTROS EL

Jueves 7 de Octubre

9:00am - 3:00pm

Autismo y Trastornos del Espectro Autista

Discusión, Sesión de Preguntas y Respuestas con

Emily Iland

De Habla Hispana, Consultora Educativa basada en Los Angeles-CA y portavoz de ASD

En el Hospital St. Christopher’s

Comuníquese con María Meléndez para hacer su reservación 267-765-0309

♦ Desayuno Continental a las 8:00 am y Almuerzo a las 12:00 del mediodía
♦ Tokens de Septa Gratuito y Parqueo Gratuito serán ofrecidos a los participantes
Role of Technology for Latino Families

- Website
- Social Networking Site
- Resources and Brochure
- Translation equipment
A Medical Home is not a building, a house, or a hospital...

...it is an approach to health care that emphasizes the partnership between pediatric clinicians and families, providing care for children and youth with special health care needs (CCYSHCN) that is:

- accessible
- continuous
- comprehensive
- family-centered
- coordinated
- compassionate, and
- culturally-effective
El Centro de Derechos Educativos
Palabras clave de recursos: educación pública, servicios, ayuda legal

Hune, Philadelphia
Palabras clave de recursos: las familias, niños excepcionales, ayuda

La Fundación para la Epilepsia
Palabras clave de recursos: las familias, epilepsia, apoyar

Lista de Control Proceso de Transición de Servicios de Cuidado de Salud
Palabras clave de recursos: juventud, de salud, transición

Los niños como defensores Auto (KASA)
Palabras clave de recursos: niños, juventud, defender sus propios derechos

Mi Pediatra (Información de Salud para Niños)
Palabras clave de recursos: niños, las familias, de salud

Red de Derechos de los Discapacitados de Pennsylvania
Palabras clave de recursos: las familias, discapacidad, ayuda legal

Seguridad de Ingreso Suplementario (SSI)
Palabras clave de recursos: las familias, ayuda financiera, de salud
Especially for Parents

• “Especially for Parents” is a web community designed with the belief that parents of children with special needs are experts who valuable insights and information to share.

• Members are able to start discussions, share tips, tricks, and shortcuts, offer support to others, write a blog, create a group for parents with similar interests or situations, create a virtual meeting spot for a local community group, promote events, and invite friends to participate.

• Community members include parents, doctors, nurses, social workers, non-profit employees, and government employees who are interested in helping children and youth with special needs reach their full potential. Practice team members are encouraged to join the community!

• To join the community, visit www.pamedicalhome.org and click on the “Parents” button. Please tell your parents about the community as well!
Key Partnerships

- Families
- Youth and patients
- Pediatric practices
- PA Dept of Health-Bureau of Family Health (Title V)
- National Center for Cultural Competency
- AAP-National Center and PA Chapter of the AAP
- National Got Transition Center
- MCHB
- Parent organizations-F2F (PEAL in PA), P2P
- Community Partners-Visions, Hune, Congresso
Thank you!

Please keep building.
Everyone deserves a medical home.

• Photo by maureen crosbie
  • http://www.flickr.com/photos/maureencrosbie/3273777533/
Emilio Pacheco, MHS
Senior Manager of Programs
Vision for EQuality, Inc.
About Vision for EQuality, Inc.

- Culturally Competent Services Through Outreach, Referral, Translation, Interpretation and Advocacy For Latino Families with Children with Special Health Care Needs
Background

- Latinos now appear to be the largest ethnic minority population in the US
- Hispanic families with CHSCN who speak Spanish as their first language are not receiving needed services
- Many of our public service systems are unprepared to meet the cultural competency needs of minority populations.
Spanish-Speaking Families’ Experiences

- Report access to services is confusing, impenetrable, and often lacking in compassion
- Do not know where to go for help
- Feel eligibility criteria are unclear
- Problems are compounded when family has a CHSCN
- Still very much under represented in terms of service response
Helpful Strategies for Program Development

- Research has shown that public education through peer-led sessions effectively addresses knowledge gap for most minority community members.

- It is well established that members of the Latino community prefer information from the people they trust and by word of mouth.
Community Collaboration
Community Collaboration

• Collaborators
  • Vision for EQuality, Inc.,
  • The PEAL Center in Pittsburgh
  • PA Chapter, American Academy of Pediatrics
  • PA Department of Health
  • EPIC IC Medical Home Initiative

• Additional Partners
  • Department of Public Welfare
  • Office of Developmental Programs
  • Philadelphia County IDS
  • Funding

We recognize the need for cultural competence within the disability community for Hispanic Families with CHSCN.
Community Collaboration

- Description

- Who we are empowering
  - Latino Families who speak Spanish as their first language
  - Families who have CHSCN
  - Families who are not receiving services or supports
Community Collaboration

- **Findings**
  - The language barrier prevents Latino families with CHSCN from accessing services that are available to them.
  - Many Latino families are unaware that there are services available to help them.

- **Constraints**
  - Funding
  - Time
  - Difficulty identifying families willing to participate
Outreach
Community Collaboration

Successes

- Families are able to receive training on topics explaining how to navigate the system
- Families are able to receive services
- Government agencies began translating and distributing resources into Spanish
- Hispanic family support group established

*Abriendo Caminos a los Latinos con Familias Excepcionales.*
Community Collaboration Services

- Receiving services allows JR and his family to be fully included in community activities.
Resource Distribution in Their own Language
Simultaneous Interpretation

- Currently, we provide translation and interpretation services as well as advocacy to the Latino population
Hispanic Parent Support Group
Advocacy and System Change

- Recommendations for the future
  - There is still much work to be done
  - Expand the project
  - Hire more Spanish speaking direct support workers, support coordinators, advocates, translators and interpreters
A VOTER Exercising His Rights
Acknowledgements

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Contact Information

• **Renee Turchi, MD, MPH, FAAP**
  St. Christopher’s Hospital for Children, Philadelphia, PA
  215-427-5331
  Renee.turchi@drexelmed.edu

• **Molly Gatto, MHA**
  PA Chapter, American Academy of Pediatrics, Media, PA
  484-446-3039
  mgatto@paaap.org

• **Suzanne C. Yunghans**
  Executive Director
  PA Chapter, American Academy of Pediatrics
  484-446-3000
  syunghans@paaap.org
  www.paaap.org
Contact Information

• **Diego Chaves-Gnecco, MD, MPH**
  Program Director
  Assistant Professor – Department of Pediatrics
  University of Pittsburgh
  Diego.Chaves-Gnecco@chp.edu
  http://www.chp.edu/CHP/spanishclinic

• **Emilio Pacheco**
  Senior Program Manager
  Epacheco@visionforequality.org

• **Myra Rosen Reynoso**
  Program Director
  National Center for Ease of Use of Community-Based Services
  Myra.rosenreynoso@umb.edu
Questions and Comments

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Thank you!

Thank you for participating in this webinar! Your feedback is very valuable. Please take a moment to complete this brief survey!
For an archived recording of this webinar and other resources, please visit www.communitybasedservices.org