Ease of Use of Services for Latino Families with CSHCN: Lessons Learned from Five States

January 25, 2014
8:00 am-11:00 am

The National Center for Ease of Use of Community-Based Services is funded by the Maternal and Child Health Bureau, Department of Health and Human Services, Division of Services for Children With Special Needs Grant No. U42MC18283
<table>
<thead>
<tr>
<th>SCHEDULE</th>
<th>SPEAKERS</th>
<th>TIME</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Introductions</td>
<td>Myra, Judy, and Veronica</td>
<td>8:00-8:10</td>
</tr>
<tr>
<td>2. Rhode Island</td>
<td>Emmanuel Echevarria and Deborah Garneau</td>
<td>8:10-8:30</td>
</tr>
<tr>
<td>3. North Carolina</td>
<td>Norma Marti, Mariela Maldonado, Monica Bernot</td>
<td>8:30-8:50</td>
</tr>
<tr>
<td>4. New Hampshire</td>
<td>Liz Collins</td>
<td>8:50-9:10</td>
</tr>
<tr>
<td>6. Indiana</td>
<td>Shirley Payne</td>
<td>9:10-10:10</td>
</tr>
<tr>
<td>7. Latino Insurance Video</td>
<td>Veronica Thomas</td>
<td>10:10-10:25</td>
</tr>
<tr>
<td>7. Break-out sessions</td>
<td></td>
<td>10:25-10:45</td>
</tr>
<tr>
<td>8. Summary</td>
<td>Myra, Judy, and Veronica</td>
<td>10:45-11:00</td>
</tr>
</tbody>
</table>
Goals of ALC

• Increase awareness and knowledge of the ease-of-use of services for Latino families and role of Title V CYSHCN implementation

• Build capacity of state health, parent and education agencies to collaborate to strengthen ease-of-use for Latino families’ efforts

• Build capacity of state health agencies to integrate efforts to make services easier to navigate for Latino families

• Facilitate change in knowledge, attitudes, practices and policies
Objectives of ALC

• Working with each grantee to identify an initial set of promising strategies based on their project that state and local MCH program could implement to improve the ease of use of services for Latino CSHCN

• Assessing possible data sources and methods that grantees could use to evaluate their proposed strategies to improve ease of use of services for Latino CSHCN

• Collaborating with a variety of partners to sustain the current project activities beyond the life of this action learning collaborate

• Disseminating information about each project and the action learning collaborative process
Ease of Use of Services for Latino Families Who Have Children and Youth With Special Health Care Needs Action Learning Collaborative
• Assists consumers with health insurance inquiries and provides holistic wraparound services.
• Enjoys a close partnership with the RI Office of the Health Insurance Commissioner and the state run health insurance exchange to address affordability, accessibility, and adequacy barriers faced by consumers.
• Supports consumers in multiple languages
• Partners with ALC to bring health coverage information and resources to families in Central Falls, RI.
• For more information, please visit www.rireach.org
Ease of Use of Services for Latino Families Who Have Children and Youth With Special Health Care Needs Action Learning Collaborative
# The Rhode Island Parent Information Network

Provides information, support, and training to help all Rhode Islanders become their own best advocate at school, in healthcare ... and in all areas of life.

## Programs
- Communities of Care
- Early Intervention Parent Consultant Program
- Family, School, and Community Engagement
- Family Voices/Family to Family Health Information Center
- Family Leadership Development Institute (FLDI)
- MegaSkills National Education Center
- Parent Training and Information Center (PTIC)
- Pediatric Practice Enhancement Project (PPEP)
- RI Insurance Resource, Education and Assistance Consumer Helpline (RI REACH)

## Support & Services
- **Workshops & Training**
  - Special Education Support
  - Transition to Adult Life (Education and Health)
  - Support Groups
    - Resources for Families with Children Who are Deaf or Hard of Hearing
    - Spanish Support Group
    - Parents of Miracles Group
    - Parents as Teachers
    - Community Information Sessions (CIS)
    - Leadership Development
      - Family Leadership Institute
      - SEAC Training

## News / Events
- **Mini-Grant Opportunity**
  - Supporting RI Early Learning & Development Standards Workshops for Parents
    - Apply by January 24, 2014
  - Click HERE for Application

- **SAVE THE DATE!**
  - College Planning Forum
    - Saturday, March 8, 2014
    - Click HERE for Brochure

- **SAVE THE DATE!**
  - Partnerships Conference
    - Wednesday, March 12, 2014
    - Click HERE for more Information

- **SAVE THE DATE!**
  - 6th Annual Dare To Dream Student Leadership Conference
    - Wednesday, May 21, 2014
    - Click HERE for more Information
### FAMILY AND COMMUNITY FACTORS IN CHILD HEALTH

<table>
<thead>
<tr>
<th></th>
<th>Central Falls</th>
<th>Newport</th>
<th>Pawtucket</th>
<th>Providence</th>
<th>Woonsocket</th>
<th>West Warwick</th>
<th>Rhode Island</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Children in Poverty</strong></td>
<td>41%</td>
<td>24%</td>
<td>25%</td>
<td>41%</td>
<td>32%</td>
<td>18%</td>
<td>17%</td>
</tr>
<tr>
<td><strong>Births to Teens Ages 15-19</strong></td>
<td>85.5</td>
<td>25.5</td>
<td>53.1</td>
<td>40.6</td>
<td>75.1</td>
<td>41.7</td>
<td>27.0</td>
</tr>
<tr>
<td>(per 1,000 teen girls)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Births to Mothers With</strong></td>
<td>37%</td>
<td>12%</td>
<td>21%</td>
<td>30%</td>
<td>24%</td>
<td>15%</td>
<td>16%</td>
</tr>
<tr>
<td>&lt; 12 Years of Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>High School Graduation Rates</strong></td>
<td>70%</td>
<td>81%</td>
<td>63%</td>
<td>66%</td>
<td>63%</td>
<td>75%</td>
<td>76%</td>
</tr>
<tr>
<td><strong>Child Abuse and Neglect Rates</strong></td>
<td>23.3</td>
<td>28.3</td>
<td>17.2</td>
<td>19.1</td>
<td>27.3</td>
<td>25.9</td>
<td>13.3</td>
</tr>
<tr>
<td>(per 1,000 children under age 18)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: *Children in Poverty, Census 2000; Births to Teens and Births to Mothers With < 12 Years of Education (2006-2010), Rhode Island Department of Health, Center for Health Data and Analysis; High School Graduation Rates (Class of 2011), Rhode Island Department of Elementary and Secondary Education; Child Abuse and Neglect, 2010, Rhode Island Department of Children, Youth and Families, RICHEIST Database.*

Source: [Disparities in Children's Health](http://www.rikidscout.org/matriarch/documents/Health%20Disparities%20IB_FINAL.pdf)

Ease of Use of Services for Latino Families Who Have Children and Youth With Special Health Care Needs Action Learning Collaborative
Ease of Use of Services for Latino Families Who Have Children and Youth With Special Health Care Needs Action Learning Collaborative
PARENT NAVIGATOR PROJECT GOAL:
Enhance the school district’s partnerships with parents and the community.

OBJECTIVE:
Work with school staff to help identify, train, and support emerging parent leaders who will serve to welcome families and strengthen the school’s connections with community.
Ease of Use of Services for Latino Families Who Have Children and Youth With Special Health Care Needs
Action Learning Collaborative
<table>
<thead>
<tr>
<th>TEAM ROLES</th>
<th>RESPONSIBILITIES</th>
</tr>
</thead>
</table>
| **10 Parent Navigators (400 hours)**  | • Engage in professional development  
Parents and family members  
Volunteer for children & families | • Welcome new families & support events  
• Update community contacts |
| **Communications Coordinator (144 hours)**  | • Email bilingual weekly updates  
Experienced parent volunteer  
Community organizing | • Mentor parent navigators  
• Present trainings & lead meetings |
| **4 Home School Liaisons**  | • Direct support at schools  
**Bilingual involvement specialists**  
family engagement in education | • Model best practice  
• Document participation |
| **Family & Community Engagement Staff**  | • Align project with district goals & protocols  
**District level Coordinator**  
Title I populations & community engagement | • Organize work flow & documentation  
• Organize meetings and trainings |
| **Project Coordinator**  | • Project management  
**Community partner**  
Developing family leadership and advocacy | • Technical Assistance |
| **RI Dept. of Health Partner**  | • Align project with statewide initiatives  
**Director of Special Health Care Needs**  
Peer support model |
LESSONS LEARNED...

• Dedicate time to build relationships (with all stakeholders)
• Demonstrate respect (be consistent and friendly, don’t assume you know)
• Be clear about your process for selection and placement of parent leaders
• Find out what motivates participants and what makes them feel valued
• Give leaders meaningful tasks and a place of their own to work
• Vary levels of support for parent leaders and staff as project develops
• Encourage parent leaders in their efforts to mentor each other
• Offer ongoing professional development opportunities based on interests
• Don’t give up, but step back and let team take on challenges
NEXT STEPS...

For Parent leaders
• Recruit volunteers and mentor new leaders
• Develop Parent Teacher Organizations
• Organize afterschool programing
• Engage in civic advocacy
• Pursue adult learning opportunities

For the district
• School principals support and collaborate with parent leaders
• Superintendent continues monthly open forums with parents
• Plan for partnership with local college to provide evening classes for parents
• Engage parents and community partners in transition to kindergarten initiative

For the community
• Maintain connections by sharing information and collaborating on projects
• Continue to work to support RI Dept. of Health initiatives
• Bring the lessons learned to our work with other communities
• Add parent leaders to list serves of information and leadership opportunities
Ease of Use of Services for Latino Families Who Have Children and Youth With Special Health Care Needs

Action Learning Collaborative
Ease of Use of Services for Latino Families Who Have Children and Youth With Special Health Care Needs

Action Learning Collaborative

North Carolina

Norma Marti
NC: Action Learning Collaborative

• Department of Health & Human Services, Division of Public Health, WCHS, Children & Youth Branch
  – Carol Tant, Branch Head, State Title V CYSHCN Director
Ease of Use of Services for Latino Families Who Have Children and Youth With Special Health Care Needs

Action Learning Collaborative

NC ALC Team: C&Y

• Marshall Tyson & Michael Sanderson, Unit Managers
NC ALC Team: C&Y II

Children & Youth Branch (NC DPH)

• Norma Martí, Minority Outreach Consultant, HC/NCHC
• Suzanne Todd, CYSHCN Helpline & Branch Family Liaison

Ease of Use of Services for Latino Families Who Have Children and Youth With Special Health Care Needs
Action Learning Collaborative
NC ALC Team: Partners

- Debbie Biggerstaff at Cabarrus Health Alliance, Innovative Approaches---Latino Family Advisory Council
  - [http://www.ccofsp.com/innovative-approaches](http://www.ccofsp.com/innovative-approaches)

- Melissa Bailey with NC FIELD, Inc., Migrant Youth Council
  - [http://www.ncfield.org/about.html](http://www.ncfield.org/about.html)

- Mariela Maldonado, Hispanic Support Groups, Autism Society of NC

- Teresa Peña & Monica Bernot, Exceptional Children’s Assistance Center
Ease of Use of Services for Latino Families Who Have Children and Youth With Special Health Care Needs

Action Learning Collaborative

NC Population: 9,752,073 (2012 estimate)
Latino/Hispanic: 8.6% (2011 estimate)

Urban

Rural
### Child Health & System Performance Disparities by Race/Ethnicity

**North Carolina**

Age 0-17 population: 2,201,857  

<table>
<thead>
<tr>
<th>Selected Child Health Indicators</th>
<th>Overall</th>
<th>Hispanic</th>
<th>Non-Hispanic</th>
<th>Black</th>
<th>White</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007 National Survey of Children’s Health</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
</tbody>
</table>

#### Physical and Dental Health

1.9: Children who currently have one or more of 16 health conditions, described by their parents as moderate or severe

<table>
<thead>
<tr>
<th></th>
<th>Overall</th>
<th>Hispanic</th>
<th>Non-Hispanic</th>
<th>Black</th>
<th>White</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>11.3</td>
<td>10.6</td>
<td>12.9</td>
<td>10.6</td>
<td></td>
</tr>
<tr>
<td></td>
<td>247,641</td>
<td>22,929</td>
<td>67,465</td>
<td>137,026</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(3.4 - 17.8)</td>
<td>(7.4 - 18.4)</td>
<td>(8.2 - 13.0)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Health Insurance Coverage

3.1: Children who currently have health insurance coverage

<table>
<thead>
<tr>
<th></th>
<th>Overall</th>
<th>Hispanic</th>
<th>Non-Hispanic</th>
<th>Black</th>
<th>White</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>91.7</td>
<td>79.2</td>
<td>91.7</td>
<td>93.9</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2,016,563</td>
<td>171,417</td>
<td>482,806</td>
<td>1,215,221</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(71.1 - 87.3)</td>
<td>(87.6 - 95.9)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3.2: Children who are currently uninsured or were uninsured at some time during the previous 12 months

<table>
<thead>
<tr>
<th></th>
<th>Overall</th>
<th>Hispanic</th>
<th>Non-Hispanic</th>
<th>Black</th>
<th>White</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>12.0</td>
<td>29.7</td>
<td>12.9</td>
<td>8.8</td>
<td></td>
</tr>
<tr>
<td></td>
<td>262,486</td>
<td>64,243</td>
<td>67,020</td>
<td>113,556</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(20.4 - 39.0)</td>
<td>(7.3 - 18.5)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3.3: Children who currently have public health insurance coverage

<table>
<thead>
<tr>
<th></th>
<th>Overall</th>
<th>Hispanic</th>
<th>Non-Hispanic</th>
<th>Black</th>
<th>White</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>34.1</td>
<td>54.5</td>
<td>61.5</td>
<td>19.8</td>
<td></td>
</tr>
<tr>
<td></td>
<td>746,137</td>
<td>114,963</td>
<td>320,591</td>
<td>255,505</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(44.1 - 64.8)</td>
<td>(53.8 - 69.1)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3.3: Children who currently have private health insurance coverage

<table>
<thead>
<tr>
<th></th>
<th>Overall</th>
<th>Hispanic</th>
<th>Non-Hispanic</th>
<th>Black</th>
<th>White</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>57.5</td>
<td>24.2</td>
<td>30.2</td>
<td>74.1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1,258,361</td>
<td>51,159</td>
<td>157,599</td>
<td>958,257</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(16.4 - 32.0)</td>
<td>(23.3 - 37.2)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3.4: Among currently insured children, those whose insurance does NOT usually/always cover child’s needs, needed providers, or enough of costs

<table>
<thead>
<tr>
<th></th>
<th>Overall</th>
<th>Hispanic</th>
<th>Non-Hispanic</th>
<th>Black</th>
<th>White</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>21.4</td>
<td>16.6</td>
<td>18.8</td>
<td>22.2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>431,596</td>
<td>28,479</td>
<td>90,546</td>
<td>270,291</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(8.7 - 24.5)</td>
<td>(12.0 - 25.5)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Previous Successes

Stefani last fall at ALC site visit (2012)

Stefani when we first met her (2007)
NC ALC Goal #1

• Completing a Spanish language podcast about the state’s children’s health insurance programs (and in 11 other languages)
  – Health Check (Medicaid) / NC Health Choice (S-CHIP)

¿Tienen seguro médico sus hijos?
NC ALC Goal #2

• Piloting a Spanish-language Liderazgo training for parents of CYSHCN by partnering with:
  – State agencies that provide services
  – Non-profit CYSHCN organizations that reach out to Latino families
  – Modules in Spanish from Vermont’s Parents as Collaborative Leaders [Link](http://www.uvm.edu/~pcl/modules.php)
NC ALC Goal #3

• Launching this training using parents as co-trainers with C&Y staff in FY 2014 in at least 5 other county health departments with large Latino/Hispanic populations and/or using a promotores model with Charlotte-Concord, Raleigh-Durham metro areas.

NOT MET IN 2012-13 ALC
What has changed over the course of the ALC time period?

- State budgets are tighter
- Systems are being shifted
  - LME/MCO [http://www.ncdhhs.gov/dma/services/lmes.htm](http://www.ncdhhs.gov/dma/services/lmes.htm)
  - ACA [https://epass.nc.gov/CitizenPortal/application.do](https://epass.nc.gov/CitizenPortal/application.do)
ALC Goal for 2013-14

• Resources Café (April)
  – Bring together existing programs (Charlotte, Raleigh, Greenville) to build on collaboration with:
    • non-profit Promotores de salud programs
      – El Pueblo
      – Amexcan
      – UNC-Charlotte
    • Migrant Ed/DPI
    • LME/MCOs

• New Collaborations
  – NAMI outreach to Latino parents (March)
  – School-Based Child and Family Support Teams training (May)
• Contact Information:
  
  – norma.marti@dhhs.nc.gov  919.707.5643
  – suzanne.todd@dhhs.nc.gov  919.707.5675
  – mbernot@ecacmail.org  704-892-1321
  – mmaldonado@autismsociety-nc.org  919-743-0204 *1114
New Hampshire

Elizabeth Collins
What We Didn’t Know

• How NH Medicaid and other state agencies identified non-English speaking recipients and provided information to these individuals

• What community locations are the most supportive (and least threatening) for hosting events and sharing information
Changes in Implementation

• In order to effectively plan activities it was important to discuss both of these issues and differences in relation to various agencies
• As we planned our information forum we discovered that the Department of Health and Human Services did not have an accessible phone system. We then needed to address this situation and ask the Department to implement a phone system that Spanish speaking families could utilize.
• We now have a plan for recommendations for the Department of Health and Human Services as well as for our Medicaid Office.
Lessons Learned

• If you are going to ask or recommend that clients/recipients make contact, it is important to actually try the system to make sure that it makes sense and is truly accessible

• The same with translating written materials with software – have someone read the materials to make sure they are clear

• We also re-worked some of our information in English prior to translation to make sure it was clear and not overly colloquial
  – For example the phrase “premium holiday” can be directly translated but it does not have the same meaning.
Primary Challenge

• Effectively identifying all of the informal community resources and their contacts, including the most receptive and convenient community locations for meetings/gatherings

• Our initiative was linked to the rollout of Medicaid Care Management. Unfortunately, that rollout has been significantly delayed and has impacted our timeline.
Ease of Use of Services for Latino Families Who Have Children and Youth With Special Health Care Needs
Action Learning Collaborative

Indiana

Shirley Payne
Ease of Use of Services for Latino Families Who Have Children and Youth With Special Health Care Needs
Action Learning Collaborative
Partners

- Title V, Children’s Special Health Care Services
- About Special Kids, Inc. (ASK)
- Family Voices Indiana, Inc. (FVIndiana)
- Early Childhood Comprehensive System (ECCS): Sunny Start
- American Academy of Pediatrics (AAP), IN Chapter
- Down Syndrome Indiana (DSI)
- Indiana LEND Program, Riley Child Development Center
- IN Commission on Hispanic and Latino Affairs
- IN Latino Institute
- Latino Coalition Against Domestic and Sexual Violence, Inc.
- La Plaza Inc.
- Autism Society of Indiana (ASI)
- Eskenazi Health (Wishard) Patient Navigation (Prenatal Care Coordination)
- Texas Migrant Council
- Parent Volunteers

Ease of Use of Services for Latino Families Who Have Children and Youth With Special Health Care Needs Action Learning Collaborative
Densely Populated Counties

Marion = 84,466

Lake = 82,663

Elkhart = 27,886

Allen = 23,093

St. Joseph = 19,395

Porter = 13,933

Tippecanoe = 12,947

Hamilton = 9,426
Ease of Use of Services for Latino Families Who Have Children and Youth With Special Health Care Needs

Action Learning Collaborative
Overarching Goals

• Create a strategic plan for ease of use of services for Latino families who have CYSHCN

• Develop an implementation schedule for the developed strategic plan
What We Didn’t Know

• This issue is VERY complex! No simple solution.

• Major barriers:
  – Lack of qualified and competent interpreters
  – Lack of cultural competency in agencies
  – Gaining access into the community
Lessons Learned

• Listen to parents/volunteers
• “Meet people where they are.”
• Make new connections
• JUST ASK!
Primary Challenge

• Moving from engagement to action

Concept  Action Plan

• Plan going forward:
  – Analyze Data from surveys
  – Invite partners to April workshop/planning session
  – Establish a beginning = strategic plan
What has changed over the course of the ALC time period?

• Strategic Plan is complete!

• New Scope
  – Implement strategies from the created strategic plan that addresses the growing needs of Latino families of CYSHCN in Indiana
Strategic Plan Implementation

• **Goal 2: Education** - In Indiana, Latinos/Hispanics and the community/social service organizations that serve them know about the needs, strengths, resources and services for children and youth with special health care needs and their families.
  
  – **Strategy C**: Develop and provide training regarding basic Spanish language for access points to health care and other resources
Questions?

Gracias
Insurance Video for Latino Families

Veronica Thomas

*Not available to public yet*
Ease of Use of Services for Latino Families Who Have Children and Youth With Special Health Care Needs Action Learning Collaborative
Gracias

National Center for Ease of Use of Community-Based Services

www.communitybasedservices.org

Myra Rosen-Reynoso
myra.rosenreynoso@umb.edu
(617)287-4370