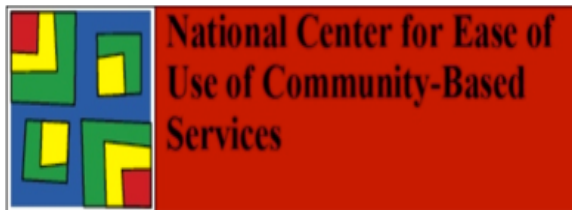


Parent-Professional Partnerships and the Ease of Use of Services for Latino Families With CYSHN in MN



Webinar Outline

INTRODUCTION	MYRA ROSEN-REYNOSO
WHY PARENT/PROFESSIONAL PARTNERSHIPS ARE IMPORTANT	BARB DALBEC
PACER'S MODEL	WENDY RINGER
MINNESOTA CONTEXT	JESUS VILLASEÑOR
FOCUS GROUPS	MYRA ROSEN-REYNOSO
LESSONS LEARNED	SHARMAN DAVIS BARRETT
Q & A	

Presenters

- Barbara Dalbec, CYSHN Director, Minnesota Department of Health
- Wendy Ringer, Coordinator, PACER's Family-to-Family Health Information Center
- Jesús Villaseñor, PACER's Multicultural Specialist and Parent Advocate and Trainer
- Myra Rosen-Reynoso, Program Director, National Center for Ease of Use of Community-Based Services
- Sharman Davis Barrett, Co-director, Technical Assistance ALLIANCE for Parent Centers

Parent-Professional Partnerships and the Ease of Use of Services for Latino Families With CYSHN in MN

Barb Dalbec

CYSHN Director

Minnesota Department of Health

Title V Role/Parent Partnerships

- Family-provider partnerships and satisfaction with service are one of the MCHB's 6 core outcomes for CYSHN
- Although parent perceptions of family-provider partnership are relatively high, satisfaction with care contributed to lower rate for the partnership/satisfaction core outcome
- Providers, families, government, and advocates need to work together for change

Key Focus Areas -- MN

- Eliminate health disparities through the removal of economic, social, and cultural barriers to receiving comprehensive, timely and appropriate care and services
- Assure highest quality of care through the development of practice guidance, data monitoring, utilization of evidence-based research, and availability of a well-trained, culturally diverse workforce

Parent Partnerships

- Brings reality into policy decisions
- Improves the quality of services and supports
- Ensures that services & supports meet the needs of CYSHN and their families

Current Activities

- Provide support to key partners
- Health Care Home includes a parent/patient advisory committee at the state level and within each certified Health Care Home Clinic/Health Center
- Outreach to key cultural community leaders in seeking volunteers for input

Lessons Learned

- Partnerships depend on relationships – basic understanding and on-going commitment to each other
- Time – it takes time to build and sustain a partnership
- Clear expectations so that everyone knows the amount of time and resources needed to complete the task or on-going commitment – whatever level is necessary to be productive and effective
- Open communication
- Diverse perspectives



PACER's Model

Wendy Ringer
Coordinator
PACER's F2F HIC
www.pacer.org

PACER's Family-to-Family Health Information Center -- MN

- F2F HICs in all states and the District of Columbia
- Staffed by parents of CYSHCN
- The Health Resources and Services Administration (HRSA), Maternal Child Health Bureau (MCHB) provides the primary funding support for F2F HICs
- This funding is currently authorized through the Affordable Care Act (ACA)

Working with Families

- Working effectively with families from diverse cultures does not require you to become a cross-cultural expert
- Does require you to be more intentional and thoughtful in your communication with parents and families who come from a culture or tradition different than your own
- The more different you are culturally from the family, the more intentional you will need to be in your communication and interaction with the family

PACER's F2F's Commitment to Employ a Strong Multicultural Team

- PACER's team of experienced multicultural parent advocates:
 - Provides individual assistance to parents through phone calls and home visits
 - Builds partnerships and outreach within communities
 - Conducts workshops for parents and professionals; and develop and translate family-friendly materials and resources for families.
- Multicultural team:
 - Dao Xiong
 - Hassan Samantar
 - Bonnie Jean Smith
 - Jesús Villaseñor

Current Activities:

State Level

- Regular communication
- Provide joint workshops and trainings
- Information sharing and dissemination
- Information line referrals
- Identify parents for participation on committees and task force membership

Current Activities:

Local Level

- Family Centered Care trainings at clinics for professionals
- Medical Home Parent Trainings
- Pediatric Resident Trainings
- Community and school group presentations
 - Resources, telling personal stories

Current Activities: Individual/Family Level

- One-on-one calls
- Home visits
- Publications – translated
- Website – audio file, links, translations





Minnesota's Context

Jesús Villaseñor

PACER's Multicultural Specialist and Parent Advocate and
Trainer

Latinos in Minnesota

Minnesota Projections By Latino Origin

Year	2000	2005	2010	2015	2020	2025
Percent of state population that is Latino	2.75	3.42	4.10	4.68	5.17	5.61

Source: State Demographic Center at Minnesota Planning

Ease of Use and Focus Groups

Myra Rosen Reynoso

Program Director, National Center for Ease of Use of
Community Based Services

Minnesota: Ease of Use of Services (Outcome # 5)

	Did NOT meet Outcome # 5	Met Outcome # 5	Avg Number of Delays for Those Who Did NOT Meet Outcome # 5
Hispanic	34.9%	65.1%	2.03
NH_White	30.4%	69.6%	1.71
NH_Black	32.9%	67.1%	2.48
NH_Other	27%	73%	1.63
MN Average	30.5%	69.5%	1.79

Source: National Survey of Children with Special Health Care Needs 2009-10

Latino Parents Speak: Focus Groups in Minnesota

- 3 focus groups: 2 in Bloomington, 1 in South St. Paul
- Participants were from: Mexico, Guatemala, Puerto Rico, El Salvador, Bolivia, Colombia, Dominican Republic, Honduras
- Forty-five families: majority were mothers, 7 fathers, 5 single moms
- Range of disabilities: autism, down syndrome, mental health conditions, genetic disorders, cystic fibrosis, intellectual disabilities

Descapacitados Abriéndose Caminos (d.a.c.)

- Established in 1994 to help Latino individuals and their families struggling with the complexities and care-giving challenges of disability
- Provides home visits, joins in doctor appointments and school team meetings, links formal and informal community resources in response to family needs and priorities, and offers informative and sustaining weekly support group sessions



Descapacitados Abriéndose Caminos (d.a.c.)

- DAC (people with disability; opening paths in life) is committed to stabilize basic needs, provide timely and culturally sensitive listening, address the families' priorities, and communicate and respond in ways meaningful to the family



Eligibility

- “You can have this, one will tell me yes and another no. I don’t know why it’s inconsistent.”
- “It’s a state benefit. I didn’t even need to call or anything, they were ready to see us. They just showed them my card when I arrived and it was all set.”

Service Availability

- “There’s another difficulty, it’s to find services near our community. Most of the services that I get you always have to go to Minneapolis.”
- “We do have good services here but all the specialists are in Minneapolis.”



Waiting Lists

- “I had to change insurance plans once my daughter reached a certain age. The new plan has a very limited list of providers so I have been waiting over a year and a half to take my daughter to the dentist.”
- “There has been a gap in services now that my daughter is older. We lost the therapy services she was getting and now she lost the ability to tie her shoes. And we just gave up on arguing for this service.”

Costs



- “Nobody told me anything. My daughter needed an operation and I had to spend all the money I earned at work...It cost \$20,000, that’s so much money...”
- “I miss a lot of work to take my son to doctor’s appointments and every time I come to work late my co-workers give me a look and my boss is not happy. I am always risking that I’m going to lose my job but there is nothing I can do about it.”

Lack of Information

- “I have two kids with special health care needs and two years ago they diagnosed my daughter and she’s already thirteen. The curious part is that in the first hospital they didn’t tell me that there were special supports for mental health needs. It wasn’t until the second hospital that they actually told me about the mental health services. I don’t know why they didn’t tell me about it in the first hospital and I wonder why one hospital is well informed and another is not...”

Lack of Information

- “When my son was diagnosed with autism, I didn’t even know what it was and the only thing the doctor told me was ‘he has Autism’. But I didn’t know what to do, I had no idea what next step to take.”
- “If you don’t ask, they won’t tell you. And you don’t know what to ask for. Even if you have a child with disabilities the school never tells you.”
- “No doctors don’t know about this type of place (referring to DAC), they know about big institutions and hospital but not this kind of place. I was taking my son to the Down Syndrome Hospital, but it was only a year ago when I discovered this place.”

Language Barriers

- “It’s not a problem to find a translator but sometimes translators don’t tell you everything the doctor is saying. That’s why I don’t miss any meetings because I need to be informed about everything in case the interpreter is missing something I interrupt him right away and I talk directly with the doctor to let him know that I know what needs to be done and what is going on.”
- “The interpreters don’t understand the real meaning of the words that we say.”

Language Barriers

- “Also, something else that’s important is that the majority of services are all in English and they establish that they don’t want to put effort into translating into your language. Many times I would request information at Children’s and it would always be in English. If it’s all in English and the parents don’t read any English, then they don’t understand! So they lose the communication. English is SO important. At the very least they should make the effort to translate all the information, so that all people have access.”

Lessons Learned

Sharman Davis Barrett

Co-director, Technical Assistance ALLIANCE for Parent
Centers

Q & A

Your feedback is very important to us. Please take a brief survey at the end of this webinar.

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Thank you for participating in this webinar! Your feedback is very valuable. Please take a moment to complete this brief [survey](#).

For more information and an archived recording of this webinar, please visit www.communitybasedservices.org