Improving Medical Homes For Immigrant Children with Special Healthcare Needs Served by FQHC's:

A New Model of Care & Parent Empowerment

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F2F/FV SAO, PTI, P2P, FFCMH, Military Family Support

SPAN

Statewide Parent Advocacy Network

Focus of our Presentation

* Engaging diverse families in medical home improvement at all stages & all levels
* Partnering to support diverse families reflective of changing demographics & health disparities
* Measuring impact

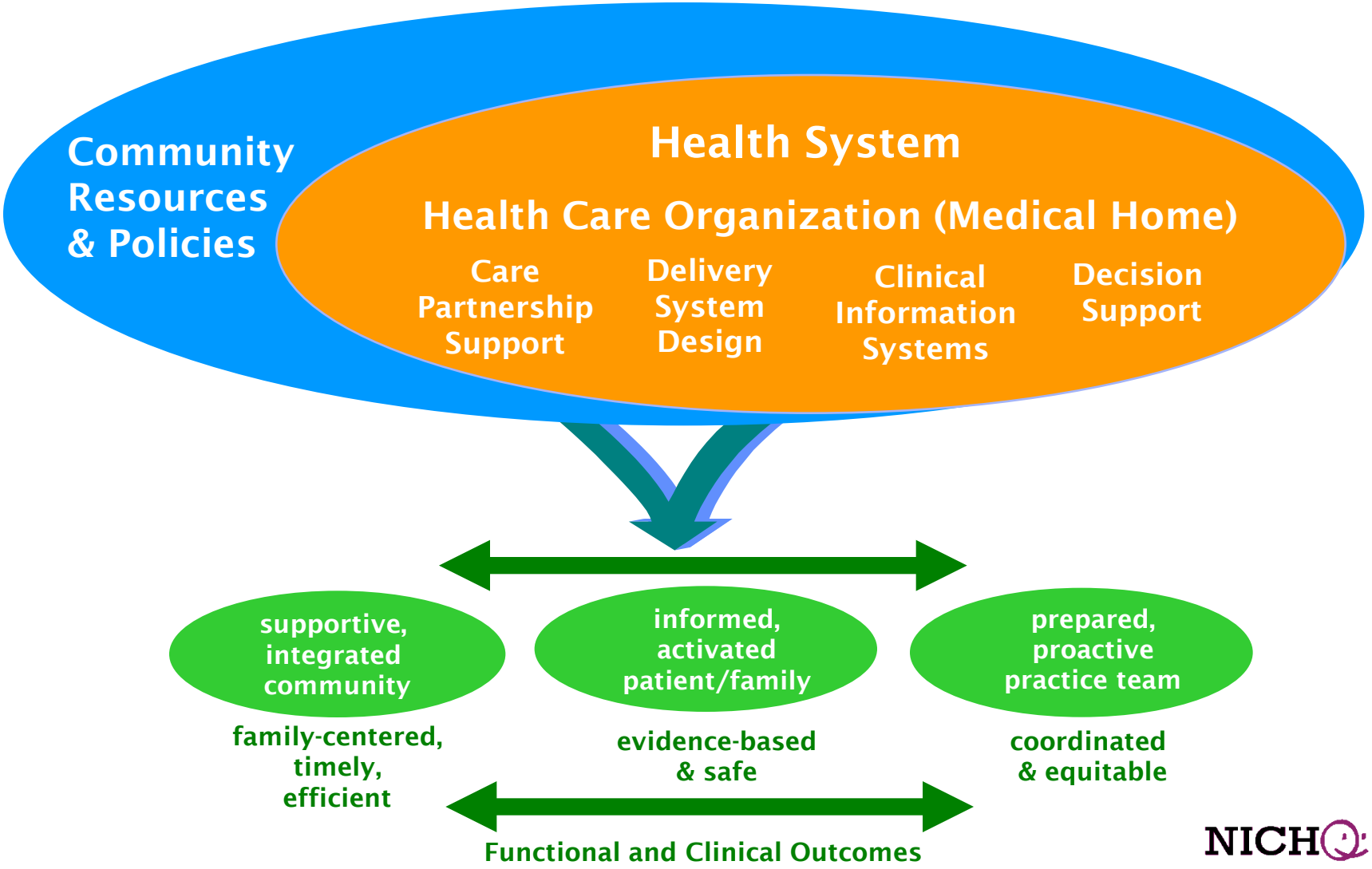
Targeted Goals

Improving access to medical homes for immigrant CYSHCN and their families in targeted high need, high immigrant/LEP communities, by enhancing the capacity of FQHCs in those communities to develop trusting partnerships and their ability to deliver care that is accessible, continuous, comprehensive, coordinated, culturally effective, and family-centered within a community-based system that provides uninterrupted care with appropriate payments to support and sustain optimal health outcomes.

Improving the ability of immigrant, underserved families of CYSHCN, including behavioral health needs, in high need, high poverty communities, to navigate health and other systems of care and increase their involvement in program planning and policy development, through outreach, engagement, education, and empowerment.

Enhancing care coordination for immigrant families of CYSHCN in targeted high needs, high poverty communities, and the care giving capabilities of immigrant families, addressing interrelated medical, social, developmental, behavioral, educational and financial needs of families to achieve optimal health and wellness outcomes

Care Model for Child Health in a Medical Home



NICHQ

Why partner with families?

* Families involved in decision making are more satisfied with their primary care provider
* Families active in developing a CYSHCN care plan are more likely to follow and maintain the care plan
* Families can tell you the types of small changes that will make a meaningful improvement

Why partner with families?

* Families know what they really need! And doctors who think they know may be wrong
  * Families rate information about community resources #1, while doctors rate it as #14
  * Families rate financial information or help #2, while doctors rate it as #5
  * Families and doctors both rate parent support groups as #3
  * Doctors rate respite and child care as #2-3, while families rate them as #9 and 21

Making It Real:
Community of Care Consortium

* Statewide collaboration of 200 key diverse stakeholders
  * Action-based workgroups on core outcomes co-led by parent & professional with parent & professional members
  * Medical home learning collaboratives with training & support co-led & co-presented by family leaders & professionals leading to positive outcomes
    * Trained diverse parent partners as members of MH Improvement teams; ongoing parent education, support groups, etc.
    * Connection to SPAN Family Resource Specialists housed at county SCHS CMUs, other SPAN services, & community resources

Ongoing Learning

* 3 full-day Learning Collaboratives for MH improvement teams in each geographic region for ~over 30 practices over 4 years
  * FQHC, Children's Hospital, primary pediatric & family practices
  * Topical panels featuring PCPs, parents, youth, community resources
* Monthly "virtual" learning opportunities
  * PCP role in IFSP, IEP, Section 504
  * Disability-specific topics (ASD, Epilepsy, etc.)
* Monthly MH Leadership Action Group calls

Key Partners

New Jersey Alliance of Family Support Organizations

NJHA New Jersey Hospital Association

Winning Angels Parent Support Organization
Serving Families and Celebrating Children With Special Needs

Family Support Center of New Jersey

Advocates for Children of New Jersey

NJPCA New Jersey Primary Care Association

NJ Council on Developmental Disabilities

Autism New Jersey

POAC The Education Leader for the Autism Community www.POAC.net

NJIPN

DRNJ Disability Rights New Jersey

NJ Health New Jersey Department of Health

SPAN Statewide Parent Advocacy Network

Department of Children and Families

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™
New Jersey Chapter

Cover our Kids Community Campaign

new jersey department of human service DHS

Integrated Systems Goals

- Leadership & structure needed for integrated system of services for CYSHCN
- Improve participation of families, *especially underserved families*, in all aspects of individual child's care & systems improvement
- Improve access to care through medical homes; early & continuous screening to identify needs; community-based services; and adequate health insurance & financing
- Increase focus on unique needs of YSHCN in transition

Factors Impacting Family Partnership

- Parents' beliefs about what is important, necessary & permissible for them to do on behalf of their children
- Extent to which parents believe they can have a positive influence on their children's services
- Parents' perception that professionals want them to be involved – *what YOU do matters!*
- Strongest & most predictive predictors are the specific practices that encourage parent involvement at all levels and guide parents

How do we get there?

- Engaging diverse families requires:
  - Vision, leadership, & investment
  - Active listening & cultural reciprocity
  - Tangible, emotional, & environmental supports
  - Mechanism(s) to track the contributions & outcomes of family engagement– "*you treasure what you measure*"

Cultural Reciprocity

- Cultures have different ways of responding to relationships, parenting, conflict, help-seeking behaviors, etc.
- Culture shapes status, relationships and social behaviors with regard to conflict resolution
- People communicate and process information differently
- Do unto others as *you* would have them do unto you.
- You can only practice cultural reciprocity if you listen with the heart… for the heart… and share your heart.

Underlying principles

- Strengths Based
- Family Centered
- Building empowerment not dependence
- Relationship-based
- Solution Focused
- Continuous Quality Improvement

Shift in Approach

- Shift from *servicing* families to *partnering* with families
- Shift from *us vs. them* to *us together against a problem*
- "If everyone is moving forward together, then success takes care of itself." Henry Ford

Starting place

* Identify small group of parents from targeted community & community cultural brokers
* Ask for their help in:
  * Understanding cultural, language, religious impacts (both sources of strength & potential barriers)
  * Developing strategies to reach, engage, & support families from their background
  * Implementing strategies
  * Evaluating progress & planning next steps
* Provide them with support

Family leaders make a difference

- NJ Outcomes
  - NJ families assisted by Family Resource Specialists demonstrate documented improvements in knowledge, confidence, competence, & skills on pre-post tests using nationally validated NCSEAM surveys
  - Practices with trained SPAN Medical Home parent partners demonstrated significant improvement in medical home-ness and family satisfaction with services on Medical Home Index-Pediatric

Measuring Our Impact

* Improvements in "medical home-ness" as evidenced by pre-post medical home surveys of quality improvement teams & families & specific improvement activities
  - W. Hudson FQHC wing of services for CSHCN
  - FQHCs sustaining parent support groups
* Development of strong parent leaders who are actively engaged in advocacy in their communities & with FQHCs
  - Advocacy & collaboration with municipalities around inclusion of CSHCN in recreational & health promotion activities
* Parent Leaders are serving as Peer Mentors at their practice and in their communities connecting families to a Medical Home and vital services.
* Parent Leaders and are actively serving on Advisory Boards with state agencies / HMO's and are active partners on the Statewide Community of Care Consortium.

Health Provider Feedback

What do health providers say?

- Over 90%:
  - Are better able to partner with parents
  - Are more knowledgeable about/connected to community resources for families
  - Feel more confident in coordinating health care services for CYSHCN

"I always knew I needed to partner with my patients' parents about their individual care, but it never occurred to me that parents could also help me improve my practice overall. Our parent partners are an incredible source of information and ideas. They know about the community resources in our area, and they know what parents need. They help us figure out what is going right, and what we need to improve. And they are an incredible resource for the other parents of children with special needs in our practice. I don't know how we ever lived without parent partners!" Pediatrician, NJ Medical Home Practice

NJ Department of Health Title V Feedback

What does NJ Title V say about our partnership?

- Over 90% of Special Child Health Services Case Managers say that Family Resource Specialists:
  - Help families partner with their child's health, education, and other service providers
  - Help families more effectively navigate community services
  - Build parent confidence & competence in getting needed services for their child

"Our collaboration-partnership is possible and effective because we have trust in each other, equality and a balance of power, a shared vision and commitment to the same goals; we highly value the contributions made by each agency; and we see the benefits to our respective agencies, but most importantly to the families and children we serve. " *Gloria Rodriguez, Assistant Commissioner, Family Health Services, NJ Department of Health and Senior Services*

Family Feedback

What do families say about SPAN's FRS?

- Over 90%:
  - Are better able to partner with their child's provider
  - Are better able to navigate community services
  - Feel more confident in getting needed services for their child

"When my child was diagnosed, I cried in the doctor's office parking lot for an hour. I felt hopeless. I was sent home with a paper that had alphabet soup written on it. None of the professionals asked me if I knew what the initials meant or what family supports I had or how I was managing with my other children. None of the professionals could imagine how isolating, sad, and confusing the whole process was. It took another parent to understand and guide me. By being paired with a parent who had "been there," and who understood my family's unique needs, it brought out the ***best*** *in me at the* ***worst*** *time in my life." NJ Latina Parent helped by SPAN*

Families: Key Partners in Progress