EXECUTIVE SUMMARY
Innovative Evidence-Based Models to Improve the System of Services for Children and Youth with Special Health Care Needs (ISG III) Evaluation Report

Introduction
This executive summary presents an overview of key evaluation findings from New Jersey’s Innovative Evidence-Based Models to Improve the System of Services for CYSHCN (ISG-III) initiative, a three-year project designed to improve the system of services for children and youth with special health care needs (CYSHCN) from underserved populations, particularly those from immigrant backgrounds in Hudson, Passaic, and Union Counties. Funded by the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB), ISG-III was a collaborative effort originally convened by a partnership between the Statewide Parent Advocacy Network of New Jersey (SPAN), the New Jersey Department of Health, and the New Jersey Chapter of the American Academy of Pediatrics (NJAAP). This partnership was expanded to form a statewide Community of Care Consortium for CYSHCN with stakeholders from state departments, community agencies, health care providers, health insurance payors, parents, youth, educators, and other interested community members, who met regularly to collectively advance and improve the system of services for CYSHCN in New Jersey.

The NJ-ISG III initiative sought to achieve three overarching goals:

1. Improve access to medical homes for immigrant CYSHCN and their families in three 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.

2. Improve the ability of immigrant, underserved families of CYSHCN, including behavioral health needs, in three targeted 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.

3. Enhance care coordination for immigrant families of CYSHCN in three targeted high needs, high poverty communities, and the care giving capabilities of 750 immigrant families, addressing interrelated medical, social, developmental, behavioral, educational and financial needs of families to achieve optimal health and wellness outcomes.
Key ISG III Activities

Medical Home Training and Technical Support
The three participating FQHC’s were trained to implement the medical home model through intensive training and technical support from a team of medical home experts. This Medical Home Resource Team worked closely with the individual FQHC medical home teams to develop and implement strategies for making quality improvements in care processes provided to CYSHCN and their families. The training included making quality improvements using the Plan-Do-Study-Act (PDSA) Cycle with focus on early developmental screening using the AAP Bright Futures recommendations, care coordination, community resources, partnering with parents and families, and specific topics such as pediatric behavioral/mental health. Because engaging parents is a critical component of the ISG III initiative, FQHC’s were expected to include a trained parent partner (parent partner training, below) on their medical home teams.

In addition to on-site training, Learning Collaboratives were held to provide a forum for information-sharing and relationship-building between FQHC providers, parents, community members, and other stakeholders. During Learning Collaborative meetings, participants shared their achievements and lessons learned in making improvements for CYSHCN through the lens of the medical home model. The initiative provided this intensive training, including the Learning Collaborative meetings, during Years One and Two, while during Year Three the initiative provided technical assistance as needed and ongoing webinar trainings in relevant medical home topics.

Parent Partner Training
Through SPAN, the initiative provided ongoing training to a group of parent partners from each of the target communities to prepare them for collaborating as partners with healthcare professionals on medical home teams. Other training topics included family advocacy, navigating the health care system, education system, and other relevant systems for CYSHCN, immigrant rights, managing caregiver stress, and other specific health and wellness topics.

Family Resource Specialists (FRS’s)
A SPAN bilingual FRS’s worked 7.5 hours each week on site at each participating FQHC. The FRS was responsible for linking FQHC staff and families with SPAN resources (education and health advocacy, training, parent leadership development, peer support, family support groups, disability-specific resources and organizations, care coordination, and other community resources); working with FQHC staff to help them more fully understand family strengths and needs and to work more effectively as partners with immigrant families of CYSHCN; and working directly with immigrant families to provide support, training and leadership development. According to the implementation plan, the FRS’s would also be responsible for ongoing support and mentorship to immigrant parent partners serving on medical home teams at each participating FQHC.
Evaluation Methods

During the planning phase of the initiative, volunteers from participating organizations formed an evaluation advisory group (EAG) to work with the evaluation consultant in developing an evaluation plan for each goal. The EAG agreed that the primary purpose for obtaining the evaluation information would be for making program improvements that support the necessary family, professional, and community partnerships to sustain an integrated system of care for CYSHCN in the target communities.

Using a participatory and utilization-focused approach,1 the evaluation consultant worked together with the EAG to determine the information that would be most useful to the initiative’s primary stakeholders. Based on the EAG’s consensus, the evaluation would have two goals: 1) to assess whether or not the four objectives were met, and 2) to obtain more in-depth information about the experiences of parents of CYSHCN, including parents who participated as members of medical home teams. It was agreed that this information produced from the evaluation would be used for program monitoring and improvement to ensure the initiative was meeting the needs of CYSHCN and their families.

The evaluation consultant worked with EAG to identify and develop a set of tools to measure the initiative’s progress in achieving its stated goals and objectives. These tools are summarized below:

**Monthly PDSA tracking form**

Developed by the medical home technical advisory group, this form collects information used to track implementation of medical home improvement activities on a monthly basis, including development of aim statements, PDSA cycles, parent partner involvement, team meetings, and lessons learned. Originally developed as a paper form, an electronic version was created using web survey software to facilitate data entry for the medical home teams.

**Medical Home Index-Pediatric Version (2001, Center for Medical Home Improvement; CMHI)**

The purpose of the MHI is to assess a practice’s “medical homeness” and to assist practices as they progress in making improvements related to the medical home model of care. It is specifically designed for use in the context of providing care to CYSHCN.

The Medical Home Index is a nationally validated self-assessment tool that rates medical homeness in 6 ‘domains’ that define a medical home: 1) organizational capacity, 2) chronic condition management, 3) care coordination, 4) community outreach, 5) data management, and 6) quality improvement/change.

Each domain includes 2 to 7 sub-domains or ‘themes’ that describe a progression of care and are expressed as a continuum from Level 1 to Level 4. Overall, there are a total of 25 themes. Theme scores are averaged for a total domain score. Total scores are then used to rank the level of

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1 See Patton, 2008.
medical home implementation from 1 (Basic) to 4 (Comprehensive). Table 1 presents the four medical home levels associated with the Medical Home Index and their interpretation:

<table>
<thead>
<tr>
<th>Level</th>
<th>Score</th>
<th>Medical Homeness</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1-2</td>
<td>Basic Pediatric Care</td>
</tr>
<tr>
<td>2</td>
<td>3-4</td>
<td>Responsive Care</td>
</tr>
<tr>
<td>3</td>
<td>5-6</td>
<td>Proactive Care</td>
</tr>
<tr>
<td>4</td>
<td>7-8</td>
<td>Comprehensive Care</td>
</tr>
</tbody>
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Source: Center for Medical Home Improvement, http://www.medicalhomeimprovement.org/knowledge/mhi-fv_instructions.html

Illinois Medical Home Family Feedback Tool (Illinois Medical Home Project).

According to the Center for Medical Home Improvement website, medical home activities cannot be fully measured without including the family perspective. The Illinois Medical Home Family Feedback Tool was designed to be used as a companion tool to the Medical Home Index. Based on the Center for Medical Home Improvement’s Family Medical Home Index and Family Survey, the NJ-ISG Medical Home Advisory Group felt that the Illinois Medical Home Family Feedback Tool was more appropriate for the ISG III patient populations because it was available in Spanish, and because the overall literacy level seemed more appropriate. Practices were asked to administer the survey to a cross section of parents of patients with special health care needs at two time points: once immediately prior to the project implementation and again following the implementation period.

It is important to note that none of the three participating FQHC’s were successful in collecting an adequate number of family feedback surveys for meaningful data analysis. This limited reporting on some grant objectives. Where possible, the Parent Health Services Satisfaction Survey results were used as an alternate data source as well as the parent focus group findings.


This tool was originally developed as part of the Developmental Surveillance and Screening Policy Implementation Project, sponsored by the American Academy of Pediatrics. The tool was designed using a quality improvement framework to assist practices in monitoring and assessing developmental screening and referral. A standard form was used to submit aggregate data at baseline and on a quarterly basis during the project implementation period to the evaluation team. Using these data, screening rates for well-visits were calculated as follows:
Well-Visit Screening Rate = total number of children screened at well visits / total number of children who came for well-visits. For this report, rates were compared at baseline and at the end of the implementation period.

**Medical Home Team Process Interviews**

A series of guided group interviews were conducted with medical home teams at each of the three FQHC’s at the end of Year Two to gauge the initiative’s implementation processes. The focus groups were conducted both on-site and via conference call, to accommodate provider scheduling and travel considerations. A set of process interview questions were developed by the EAG during the initiative’s planning phase. The interviews were facilitated by a team of SPAN and NJ AAP staff.

**Parent Partner Focus Groups**

To gain in-depth understanding of parent experiences with the initiative, focus groups were conducted at the beginning and end of the implementation period with parents who had received the parent partner training. A set of focus group questions were developed by the EAG during the initiative’s planning phase and translated into Spanish by the focus group facilitator. (see Appendix for focus group questions and transcripts).

**Parent Health Services Satisfaction Survey**

At the end of the program implementation period, a patient satisfaction survey was administered to parents of patients who had received services that were directly related to specific quality improvement projects at participating FQHC’s. It is important to note that because Neighborhood Health Services’ quality improvement projects during Year Three were related to obtaining newborn records from birthing hospitals, a patient survey was not conducted, since parents satisfaction was not a direct outcome from this improvement activity. Therefore, results are only presented for NHCAC–Hudson and NHCAC—Passaic.

**Key Stakeholder Interviews**

Individual interviews were held with key stakeholders throughout the implementation period. Key stakeholders included key SPAN staff, the medical home technical assistance team, and co-convening organization representatives.

**Pre-Post Survey for Families Who Receive Intensive Support (EI Family Outcomes Survey)**

This 15-item pre-post questionnaire measures parent self-confidence, self-competence, knowledge of resources, and caregiving capacity. The items are presented as a series of statements in a Likert format with respondents answers based on a 5-point scale consisting of strongly disagree, disagree, no opinion, agree, and strongly agree. The tool is a modified version of the National Center for Special Education Accountability and Monitoring (NCSEAM) Family Survey – Early Intervention.

**Parent Partner Training Evaluations**

The parent partner training evaluation is a brief post-test only tool developed by SPAN sand
administered to participants following each of the initiative trainings. The first part of the tool consists of three questions designed to assess participant ratings of the usefulness of the training content, materials, resources and tools using a 4-point scale (not useful, somewhat useful, very useful, extremely useful), while the second part asks participants to identify the learning outcomes of the training.

**Program Document Review**

A review of program documents including workgroup meeting minutes, sign-in sheets, training curricula, presentation slides, resource guides and other materials was conducted to support the assessment of the initiative’s implementation and progress.

**Key Findings and Lessons Learned**

**Key Findings by Goal**

*Goal 1: Improve access to medical homes for immigrant CYSHCN and their families in three 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.*

- One FQHC from each of the three target communities was successfully recruited to participate in the initiative:
  - North Hudson Community Action Corporation Community Health Center--Passaic (NHCAC; Passaic County),
  - North Hudson Community Action Corporation Community Health Center (NHCAC—Hudson; Hudson County), and
  - Neighborhood Health Services (NHS; Union County).
- All three participating FQHC’s successfully improved the use of AAP-recommended tools as well as screening rates for early developmental screenings at the 9-, 18-, and 24-month well visits, as follows:
  - While NHCAC—Passaic was already successfully screening all children at the 9-, 18- and 24-month well-visits at baseline, they improved their use of AAP/Bright Futures-recommended tools by incorporating the M-CHAT into their 18- and 24-month screening protocols.
  - NHCAC--Hudson was successful in improving early developmental screening for children at the 9-month and 18-month well-visits. (However, the number of children
who came for 24-month well visits was too small to assess changes in screenings at this age.

- NHS—Union improved screening rates at the 9- and 24-month well visit and maintained their baseline 100% screening rate for 18-month well visits throughout the initiative implementation period.

- Two of the three participating FQHC’s improved their scores on the Medical Home Index from Year One to Year Three:
  - NHCAC—Passaic increased from a Level 1 to a Level 2 Medical Home.
  - NHCAC—Hudson remained at a Level 2 Medical Home.
  - NHS increased from a Level 2 to a Level 3 Medical Home.

**Goal 2: Improve the ability of immigrant, underserved families of CYSHCN, including behavioral health needs, in three targeted 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.**

- The initiative achieved its target of providing 750 immigrant families with training and peer-to-peer support. The parents attended trainings on a number of topics related to family needs across systems, including rights of immigrants/language access; organizing medical and educational records, managing caregiver stress, positive behavior support/managing difficult behaviors at home and in the community, parent leadership and advocacy. During Women’s Health Week, the initiative delivered several health and wellness educational sessions and activities, including mobile van cholesterol and blood pressure screenings, food demonstration sessions with a nutritionist, Zumba, and vision screening.
  - In Passaic, a total of 608 parents attended 29 trainings.
  - In Hudson, a total of 863 parents attended 29 trainings.
  - In Union/Elizabeth, a total of 68 parents attended 9 trainings. (Note: this group was smaller due to a shortened training implementation schedule).

- Based on data from the parent partner training evaluation forms used in all three initiative locations (Passaic, Hudson, and Union/Elizabeth), for every training conducted, 100% of the parent participants rated the training content materials, resources and tools (combined) as “extremely useful,” the highest possible rating.

- Across all the trainings in each of the three initiative locations, 100% of parents who attended indicated the training had effectively increased their skills to collaborate with professionals, their understanding of systems and services, their ability to effectively advocate or navigate, ability to apply or access programs and services, request resources
and referrals, understand their rights and role as parents, and integrate their child with special needs in the community.

- Focus groups conducted with parents supported the quantitative findings, with parents expressing appreciation for increased skills in partnering with healthcare and other professionals, improved advocacy, improved family health and well-being and connection with other parents.

**Goal 3: Enhance care coordination for immigrant families of CYSHCN in three targeted high needs, high poverty communities, and the care giving capabilities of 750 immigrant families, addressing interrelated medical, social, developmental, behavioral, educational and financial needs of families to achieve optimal health and wellness outcomes.**

- All three FQHC’s successfully improved care coordination as evidenced by an improvement from Year One to Year Three in the care coordination domain score of the Medical Home Index. On a scale of 1 (basic pediatric care) to 8 (comprehensive pediatric care):
  - NHCAC—Hudson’s score improved from 3.3 at baseline to 3.7 at the end of the Year Three;
  - NHCAC—Passaic’s score improved from 2.0 at baseline to 3.7 at the end of Year Three; and
  - NHS’s score improved from 3.3 at baseline to 5.5 at the end of Year Three.

- Based on data from the EI Family Outcomes Survey, 90% or more of participating immigrant parents of CYSHCN in each of three target communities showed an increase from baseline to post-initiative implementation in 10 or more of the 15 family outcomes related to care giving capabilities as measured by the EI Family Outcomes Survey, including parent self-confidence, self-competence, knowledge of resources, and capacity to navigate health and other systems of care and advocate on behalf of their child(ren) and family.

**Lessons Learned**

- The initiative used a model for medical home implementation that had been successfully implemented in at least two other large-scale systems improvement initiatives in New Jersey. However, at the time ISG III was implemented, the FQHC’s were involved in meeting the many new requirements and policy changes related to the Affordable Care Act, including transitioning to the use of EMR systems. The challenge of meeting these new requirements made it difficult and overwhelming at times, for the FQHCs to allocate sufficient staff and time resources to implementing this project. In the future, a scaled-down version of this model with less provider data collection requirements might be more realistic for FQHC participation.
• Although the family feedback survey selected by the Evaluation Advisory Group for its availability in Spanish, appropriate literacy level, and shorter length compared to other tools, focus group feedback from the medical home teams indicated that it was still considered too long. There is a need in the medical home literature for a shorter instrument to measure patient satisfaction with the medical home that is available in Spanish and appropriate for patients with lower literacy levels.

• None of the three FQHC’s was able to consistently engage a parent partner to participate on their medical home team during the initiative. Based on interviews with program staff and the medical home teams themselves, the reasons for this lack of engagement appear to be many-sided and complex. While the medical home teams, program staff, and program partners expressed positive attitudes about parent partners and understood the importance of parents partners on the medical home team, it is the evaluator’s opinion that more time was needed to build relationships and trust between the medical home professionals and the parents in order to fully engage with parent partners as active members of the medical home teams. However, the FQHC’s readily engaged the FRS’s and integrated them as practice team members. The FRS's obtained FQHC organizational ID’s and were included in team meetings, staff center meetings, and community events. The FQHC’s referred families of CYSHCN to the FRS’s and collaborated with the FRS to plan and promote activities centered on family engagement. The role of the FRS appeared to work better with the FQHC model of practice with respect to professional/referral-based services within a social service model.
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