ECCS State Advisory Team (SAT) Quarterly Meeting
March 13, 2020
10:00-11:00 am

If you’re having technical difficulties please contact Ciearra Norwood, ciearra.Norwood@ccf.ny.gov

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Thank you State Advisory Team Organizational Members!
Agenda:

• Introductions
• Year 4 Meeting Schedule
• Impact Grantee Update
• Ramirez June Developmental Disabilities Navigator Initiative
• Community Update
SAT Year 4 Meeting Schedule

- September 13, 2019
- December 6, 2019
- March 13, 2020
- June 12, 2020
Impact Grantee Update

SUNY RF
The Research Foundation for
The State University of New York

ECCS
NYS Early Childhood Comprehensive Systems

NEW YORK
STATE OF OPPORTUNITY
Council on Children and Families

Docs FOR TOTS
5 YEAR AIM
Improve developmental skills of 3 year old children by 25%
Plans for Year 4

• Partner Tool Survey

• Attend conferences relevant to the ECCS work

• Support placed-based communities with Learn the Signs. Act Early. materials

• Provide cultural competency and health literacy training in placed-based communities

• Connect with state partners
PARTNER Tool (Program to Analyze, Record, and Track Networks to Enhance Relationships)

What: Designed to measure collaboration among organizations (i.e. how members are connected, how resources are leveraged, exchanged and the levels of trust between them)

Outcome: By using the tool, we will be able to demonstrate how our ECCS CoIN has changed over time and the progress made in how community members and organizations participate.
PARTNER Tool

1. Email link invitation
2. Instructions & Consent
3. Find your organization
4. Answer questions 2-20
PARTNER Tool

• The survey takes about 30 minutes to complete

• You can log in and log out! It does not need to be completed in one sitting

• Once the survey is open you have a month to complete it

• If you don’t receive the email invitation by Tuesday, March 17, 2020 check your junk mail

• Call (518-408-4107) or email (ciearra.Norwood@ccf.ny.gov) with any questions!
Learn the Signs. Act Early. @ NYAEYC
April 2-4, 2020 | Verona, NY

COMES VISIT THE LTSAE BOOTH!

Melissa Passarelli, MA
Director of Programs, Docs for Tots & New York State Act Early Ambassador

melissa@docsfortots.org
We want to hear from you!

Let us know if there are any events, resources, and/or initiatives related to developmental health that we should know about.
Ramirez June Developmental Disabilities Navigator Initiative

Chinese-American Planning Council, Brooklyn, NY

Consulate of Paraguay, NYC
Cynthia Stewart, M.S.
Ramirez June Developmental Disabilities Navigator
NYS Office for New Americans
Cynthia Stewart, M.S.

- Master of Science in Mental Health Counseling from SUNY New Paltz
- Provided therapy for youth and adults with developmental disabilities as a clinical intern
- Supported individuals with developmental disabilities to achieve their goals as a direct support professional for the ARC Mid-Hudson
New Member of the NYS Early Childhood Comprehensive Systems (ECCS) State Advisory Team
Agenda

1. The Office for New Americans (ONA)
2. The Ramirez June Developmental Disabilities Navigator Initiative
3. 2020 Census #DisabilityCounts2020
NYS New Americans
NYS New Americans

Foreign-born: 4.4 Million
(25% of NYS residents)

Unauthorized immigrants: 870,000
Non-citizens in NYS are eligible for NYS health insurance

• Except for undocumented / out-of-status
  – Undocumented individuals can access sliding scale & charity care, emergency Medicaid, and coverage for pregnant individuals until 60 days post-partum

Source: Aliessa et al. v. Novello, 2001
What are the 6 most common non-English languages in NYS?

Ramirez June 发育障碍指导项目
Andikap Devlopmantal Ramirez June Inisyativ Navigatè
Ramirez June 发育障碍指导项目
Программа по отклонениям в развитии имени Рамирес Джун Управляющий инициативы
Ramirez June Iniciativa Para Personas Con Discapacidades del Desarrollo
6 Most Common Non-English Languages in NYS

1. Bengali
2. Chinese (Cantonese & Mandarin)
3. Haitian Creole
4. Korean
5. Russian
6. Spanish

Source: Executive Order 26
ONA’s Beginnings

Governor Andrew M. Cuomo established the Office for New Americans (ONA) in 2013 to assist newcomers to New York State who are eager to contribute to our economy and become part of the family of New York State.
ONA Program Overview

- Opportunity Centers
- Legal Counsels
- Liberty Defense Project
- Cell-Ed
- Navigators
- Golden Door
- Ramirez June Developmental Disabilities Navigator
New Americans’ Hotline

1-800-566-7636

Information and referrals are available through the toll-free, multilingual New Americans Hotline

• 9 a.m.-8 p.m., Monday to Friday
• Anyone can call the hotline for information and referrals
  • Any citizenship or documented status
• Confidential and anonymous
• Assistance available in 200+ languages
Ramirez June Developmental Disabilities Navigator Initiative

- Grantee of the Developmental Disabilities Planning Council (DDPC)
- 100% federally funded 3-Year initiative
- New York State-based
- Partnered with OPWDD
- Informed by the experiences of the Ramirez family and the family of Siewling (June) Lum
Initiative Mission

• Expand access to culturally and linguistically competent services and resources for new Americans with developmental disabilities (all ages)
• Combat stigma; increase inclusivity and pride
• Identify and prevent human trafficking of new Americans with developmental disabilities
Deliverables for 3-Year Initiative

• Conduct targeted outreach, webinars, community engagement
  – Engagement of at least 200 individuals including those with developmental disabilities, hear and address concerns
  – Outreach to new Americans in rural areas

• Identify 2 Partners

• Collect demographic data
Developmental Disabilities Overall are More Common in Rural Areas

Notably higher rates of children diagnosed with cerebral palsy and ADHD

Source: Center for Disease Control and Prevention (2020)
Prevalence of Developmental Disabilities

Rural Locations: 19.8%

Urban/Suburban Areas: 17%

Source: Center for Disease Control and Prevention (2020)
Nearly one-half (49%) of children with DD in rural areas did not see a:

1. mental health professional
2. specialist, or
3. therapist

in the past 12 months

Source: Center for Disease Control and Prevention (2020)
One-third of pediatricians in the U.S. do not conduct developmental screenings

New Americans

Developmental Disabilities
What will affect a new American family’s experience with supportive services?
New Americans with DD

- Immigration Status
- Urbanicity
- Culture & Spirituality
- Mental & Physical Health, Trauma History
- Language
- Socioeconomic Status (SES)
New American Family: May & Kang

- May’s eldest son Kang has a developmental disability, but was not connected with the Early Intervention Program until he was 2 years old and 3 months
  - "At that point, nobody wanted to take the case“- May
- Kang was placed in a Special Education program 1.5 hours away
  - "We know what's best for your child, we are professionals"
- May and Kang waited years to be connected with OPWDD services after applying.
- While raising Kang, May did not see a doctor for 10 years until she received her green card
Concerns

• Lack of bi-lingual providers overall
• Students with limited English proficiency not having their needs met in school
• Lack of developmental screenings for new Americans, especially refugees and asylees
2020 Census
#DisabilityCounts2020

CDC estimates 1 in 6 children has a developmental disability

– This estimate **does not** determine funding for programs that support individuals with developmental disabilities
US Census Bureau: “The 2020 Census is Accessible for Everyone”

- **Online Section**
  - 508 Compliant and a video guide in American Sign Language
- **By Phone**
  - Telephone Device for the Deaf (TDD/TTY) technology
- **By Mail**
  - Braille and large print language guides (“Sample Ballots”)
Ramirez June Developmental Disabilities Navigator Initiative

If you would like to connect with this initiative or schedule a presentation, contact: (518) 242-0402, or cynthia.stewart@dos.ny.gov
Please raise your hand to speak or type in the chat box to share!
Place-Based Community Update: Nassau County

Liz Isakson, MD, FAAP
- Executive Director
- ECCS Place-Based Community Lead
- contact: liz@docsfortots.org

Melissa Passarelli, MS
- Director of Programs
- ECCS Place-Based Community Lead
- contact: melissa@docsfortots.org
HIGHLIGHTED UPDATES- SCREENING DATA

12/6/19-3/6/20
### Aggregated ASQ-3 Results, 2018-2020

<table>
<thead>
<tr>
<th>Score</th>
<th>Overall</th>
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<tbody>
<tr>
<td></td>
<td>#</td>
<td>%</td>
</tr>
<tr>
<td>Above Cutoff</td>
<td>884</td>
<td>52%</td>
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<tr>
<td>Monitoring</td>
<td>389</td>
<td>23%</td>
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<tr>
<td>Below Cutoff</td>
<td>420</td>
<td>25%</td>
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<tr>
<td>Total</td>
<td>1693</td>
<td>100%</td>
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<table>
<thead>
<tr>
<th>Score</th>
<th>ASQ Partner Sites</th>
<th>CAP</th>
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<tr>
<td></td>
<td>#</td>
<td>%</td>
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<tr>
<td>Above Cutoff</td>
<td>848</td>
<td>55%</td>
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<tr>
<td>Monitoring</td>
<td>349</td>
<td>23%</td>
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<tr>
<td>Below Cutoff</td>
<td>340</td>
<td>22%</td>
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<tr>
<td>Total</td>
<td>1537</td>
<td>100%</td>
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### ASQ-3 Scores by Domain, 2018-2020

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Score Result</th>
<th>Total</th>
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<tbody>
<tr>
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<tr>
<td><strong>ASQ: Communication</strong></td>
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<tr>
<td>Above Cutoff</td>
<td>1330</td>
<td>79.3</td>
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<td>Monitoring</td>
<td>169</td>
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<tr>
<td>Below Cutoff</td>
<td>179</td>
<td>10.7</td>
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<td><strong>Total</strong></td>
<td>1678</td>
<td>100</td>
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<tr>
<td><strong>ASQ: Gross Motor</strong></td>
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<tr>
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<td>83.1</td>
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<tr>
<td>Monitoring</td>
<td>145</td>
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<tr>
<td>Below Cutoff</td>
<td>140</td>
<td>8.3</td>
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<tr>
<td><strong>Total</strong></td>
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<td>100</td>
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<tr>
<td><strong>ASQ: Fine Motor</strong></td>
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<td>1190</td>
<td>71.2</td>
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<td><strong>Total</strong></td>
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<td><strong>ASQ: Problem Solving</strong></td>
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<td>81.2</td>
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<td>8.4</td>
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<tr>
<td><strong>Total</strong></td>
<td>1677</td>
<td>100</td>
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<tr>
<td><strong>ASQ: Personal Social</strong></td>
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<td>82.3</td>
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<tr>
<td>Monitoring</td>
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<td>10.0</td>
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<td><strong>Total</strong></td>
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## ASQ-SE Results

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<th>ASQ-SE Score</th>
<th>Total Children Served</th>
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<td>#</td>
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<tr>
<td>Typical</td>
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<td>Monitoring</td>
<td>60</td>
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<tr>
<td>Behavioral concern</td>
<td>53</td>
</tr>
<tr>
<td>Total</td>
<td>451</td>
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EARLY LEARNING SCREENING COLLABORATIVE

Background
- HMG National Community of Practice
- In partnership with LI’s 2 CCR&Rs and QUALITYstarsNY
- Support from OCFS

2 simultaneous cohorts launched in October 2019
- Directors of early learning centers
- One in each county
- 4 in-person meetings over the course of 3-4 months, with individualized site visits/TA in between
- Focus on training directors in QI, empowering them to train their staff on developmental promotion and screening, and changing policies/procedures to incorporate this going forward

Plans to replicate with family providers and pre-Ks
ISSUE TRENDS: CONNECTING FAMILIES TO EI/CPSE

- Hardest for new American families (Spanish speaking)
- Barriers:
  - EI
    - Uneasiness with the “government” having their information
    - Spanish-speaking staff are not always available
    - Have to fill out and return paperwork before they can proceed; some forms not available in Spanish, even if literacy isn’t an issue
  - Requesting CPSE services
    - 125 school districts with different paperwork/processes
    - Often don’t have translated forms
    - Some require 3 forms of proof of residency, which is challenging for many families
    - Many don’t answer phone calls and require you to go to the school, which is challenging for those without transportation and/or who work during the day
    - Appointments are made via mail- families often live in multi-family homes and do not have ready access to their mail
- Example
Questions for SAT

- How can we better help all families access EI and CPSE services?
  - Are there levers at the state level?
  - Are there local options that have not been explored?
Please raise your hand to speak or type in the chat box to share!
Place-Based Community Update: Western New York

Dennis Kuo, MD, MHS
- Associate Professor and Division Chief, General Pediatrics, University at Buffalo
- Medical Director of Primary Care Services at Women & Children's Hospital of Buffalo
- ECCS Place-Based Community Lead
- Contact: dkuo@upa.chob.edu

Lea Passage, MHA
- Early Childhood/Population Health Project Coordinator, UBMD Pediatrics
- ECCS Place-Based Community Lead
- Contact: lpassage@upa.chob.edu
WNY ECCS COIIN UPDATE

1. Data review
2. Referral Tracking
3. Cultural Competency
4. Spread and Sustainability
ECCS DATA REVIEW
TOWNE GARDENS

% Conducted
Towne Gardens

% Referred
Towne Gardens
• Towne Gardens, Niagara Street and Main Pediatrics have been tracking and collecting data on all referrals made to Erie County Early Intervention

• Recently trained Tonawanda Pediatrics to track all referrals to Niagara County Early Intervention

• Presented referral tracking and data collection process to Pediatrics Supporting Parents Learning Community (2/27/2020)
ASQ Referral Tracking Niagara Street, Towne Gardens, Main Pediatrics (n= 43)

Reason Evaluation Not Completed (n=14)
- Parent Refusal
- Unable to Contact Family
- Scheduling Issues
- Parent did not follow through
- Refused by EI
- System navigation issues
- Family Moved

Outcome
- Evaluation Completed
- Evaluation Not Completed
- Unknown (no consent)
Based on this data, how can we increase evaluation rates for referrals to Early Intervention?

1. Informational materials
   • Provide parents with more information to take home about Early Intervention

2. Increase awareness
   • Provide training/presentations to staff and providers that include parent stories

3. Improve trust and motivation among the community
   • Provide cultural competency training to break down barriers between patients/parents and staff/providers
CULTURAL COMPETENCY TRAINING

• CoILN quarterly meeting- Jericho Road Community Health Center presentation
  • Jericho Road’s Mission: provides holistic healthcare for the underserved and marginalized communities in Buffalo and across the world in order to demonstrate the unconditional love of Jesus.

• Objectives:
  o Review background and importance of cultural competence in health care
  o Learn about the cultural competency training process at Jericho Road (presentation)
  o Discuss ways to incorporate best practices for cultural competency in your organization
  o How will an increase in cultural competency help our ECCS Learning Collaborative?

• Currently reviewing two other community agencies for a follow up training session
  • CCNY
  • International Institute of Buffalo
SPREAD AND SUSTAINABILITY

• Presentations
  • Grand rounds- Oishei Children’s Hospital of Buffalo, 3/6/2020
  • Buffalo Pediatric Society presentation- 3/25/2020
  • Screening Toolkit
Please raise your hand to speak or type in the chat box to share!
Contact:

Ciearra Norwood, Project Coordinator
ciearra.norwood@ccf.ny.gov
(518) 408-4107

Vicki Robert, Early Childhood Social Emotional Coordinator
vicki.robert@ccf.ny.gov
(518) 474-9023

Website
www.ccf.ny.gov