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FINAL REPORT

Activities of the American Academy of Pediatrics in the Zika Program of the USAID Applying Science to Strengthen and Improve Systems (ASSIST) Project in the Eastern and Southern Caribbean

JANUARY 2020

This final report on support to the Zika program in the Eastern and Southern Caribbean was prepared by University Research Co., LLC (URC) for review by the United States Agency for International Development (USAID) through the USAID Applying Science to Strengthen and Improve Systems (ASSIST) Project, which is made possible by the generous support of the American people through USAID. It was authored by the American Academy of Pediatrics.

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DISCLAIMER

This final report was authored by the American Academy of Pediatrics. The views expressed do not necessarily reflect the views of the United States Agency for International Development or the United States Government.

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For more information on the work of the USAID ASSIST Project, please visit www.usaidassist.org or write assist-info@urc-chs.com.

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Acronyms

AAP	American Academy of Pediatrics
ASSIST	USAID Applying Science to Strengthen and Improve Systems Project
CDC	U.S. Centers for Disease Control and Prevention
CSaZ	Congenital Syndrome associated with Zika
ECHO	Extension for Community Healthcare Outcomes
ECEB	Essential Care for Every Baby
MOH	Ministry of Health
NDS	Neurodevelopmental surveillance
QI	Quality improvement
STTA	Short-term technical assistance
TA	Technical assistance
USAID	United States Agency for International Development
ZiCaMas	Zika Case Management tool

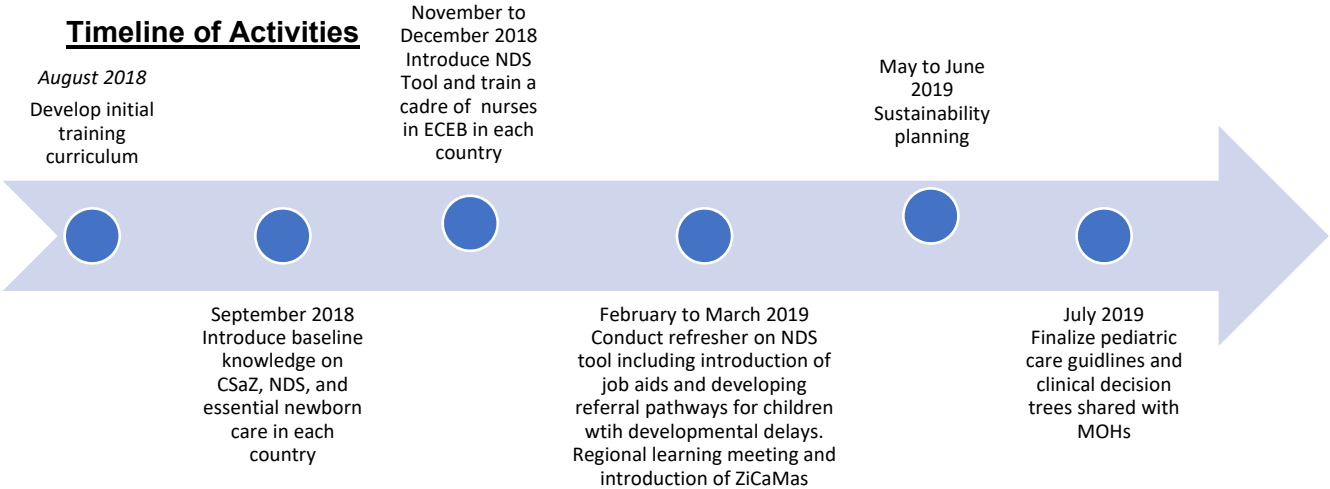
1 Introduction

The USAID Applying Science to Strengthen and Improve Systems (ASSIST) Project partnered with the American Academy of Pediatrics (AAP) to support four Ministries of Health (MOH) in four Eastern and Southern Caribbean islands—Antigua & Barbuda, Dominica, St. Kitts & Nevis, and St. Vincent & the Grenadines—to respond to the increased needs of the newborn and well-child care systems in light of the Zika epidemic. The period of AAP performance was August 29, 2018 – July 31, 2019.

Since the outbreak of Zika virus in 2016, the AAP has been a leader in the United States (U.S.) response. The AAP, through our Committee on Infectious Disease, Disaster Preparedness Advisory Committee, and other sub-specialty committees, has been instrumental in advising the U.S. Centers for Disease Control and Prevention (CDC) and partnering with them to develop interim guidance for diagnosis and screening of Zika. The latest evidence on the impact Zika may have on exposed infants was published in a supplement to AAP’s journal, *Pediatrics*, in February 2018 () which included up-to-date evidence on ocular manifestations, motor abnormalities, and epilepsy associated with Zika infection as well as the possible long-term impact on public health and care. In addition, the AAP has disseminated the AAP/CDC guidelines through webinars on screening, diagnosing, evaluating, and managing Zika virus infection in infants and children and has produced tools and resources in coordination with CDC. Since February 2017, the AAP has held regularly occurring Zika Extension for Community Healthcare Outcomes (ECHO) tele-mentoring sessions, which connect a faculty team of experts with primary care providers in the U.S. territories most affected by Zika virus; over 200 physicians have participated to date. AAP’s tele-mentoring efforts have been complemented by technical assistance visits to Puerto Rico and the U.S. Virgin Islands, as well as remote technical assistance to the Health Department in America Samoa, to improve detection and adapt national guidelines to these low-resourced territories.

In order to support each Eastern and Southern Caribbean MOH’s response to the Zika epidemic, particularly children potentially affected by Congenital Syndrome associated with Zika (CSaZ), the AAP utilized a multi-pronged approach to reach both policy and practice levels of the health system. At the policy level, the AAP provided recommendations to the national Zika care guidelines, backed in up-to-date science beyond currently published global and national recommendations from the World Health Organization/Pan American Health Organization (WHO/PAHO) and CDC, and refined based on specific needs of the country health systems accounting for availability of diagnostic tools, specialty providers, and routine child health care. At the practice level, AAP developed new surveillance tools and job aids, a training curriculum linking pediatric Zika care to AAP’s Essential Care for Every Baby (ECEB) curriculum, routine well-child care (6 weeks to 6 years), and neurodevelopmental surveillance (NDS), reaching nearly all public child health providers on each island and training a core set of champions for both essential care for every baby and neurodevelopmental surveillance.

Timeline of Activities



Key Personnel

To implement the USAID ASSIST Eastern and Southern Caribbean activities over the past 12 months, the AAP employed a multi-disciplinary team of staff and AAP-member consultant experts:

Terrell Carter, MHS—Director Global Child & Adolescent Health provided overall project oversight and delivered on-the-ground technical assistance.

Hannah Foehringer Merchant, MPH—Program Manager Global Child Health Initiatives provided ongoing technical and programmatic oversight

Beena Kamath Rayne, MD, MPH, FAAP—Essential Newborn Care Advisor provided curriculum development, in-person technical assistance (TA) and training, and remote technical support

Kera McNelis, MD, MS, FAAP—Essential Newborn Care Advisor provided curriculum development, in-person TA and training, and remote technical support

Nina Prasanphanich, MD, PhD, FAAP—Essential Newborn Care Advisor provided curriculum development, in-person TA and training, and remote technical support

Susanne Martin Herz, MD, PhD, FAAP—Neurodevelopmental Care Advisor provided curriculum development, in-person TA and training, and remote technical support

Alcy Torres, MD, FAAP—CSaZ Advisor provided remote technical support around adaptation of Zika care guidelines to country contexts

As a result of AAP training and technical assistance:

- All public health providers responsible for well-child care were trained in updated neurodevelopmental surveillance with improved sensitivity and specificity, ultimately improving identification of children with delays possibly due to CSaZ from birth to school age in all four countries.
- A cadre of nurse midwives was trained as Essential Care for Every Baby Trainers and Well Child Care champions, establishing a coordinated system of care from birth to school-age for children possibly exposed to Zika in all four countries.
- Three countries—Dominica, St. Kitts & Nevis, and St. Vincent and the Grenadines—received evidence-based recommendations for clinical management of newborns born during a time of Zika transmission adapted for available diagnostics and health workforce capacity.

2 Results

Updated Zika care guidelines and associated health facility tools

AAP's team of Technical Advisors, in close collaboration with the USAID ASSIST team, reviewed the existing national pediatric guidelines and developed a set of recommendations based on updated knowledge of the Zika virus, CSaZ, and appropriate follow-up. This updated knowledge came from WHO/PAHO guidelines (2016 and 2018), 2018 updated CDC guidance, on-going engagement in CDC technical working groups, and the August 2018 *Vital Signs*¹ publication analyzing data collected in United States (all states and territories) which provided significant evidence on the potential outcomes of CZaS.

Overall recommendations and updates fell into two categories—clinical description of CSaZ and clinical management. The initial national protocols focused significantly on microcephaly as the key factor that

¹ CDC MMWR, Vital Signs: Zika-Associated Birth Defects and Neurodevelopmental Abnormalities Possibly Associated with Congenital Zika Virus Infection— U.S. Territories and Freely Associated States, 2018.

defines CSaZ. While microcephaly is one of the CSaZ-defining abnormalities/delays, current evidence shows that only 4% of babies with CSaZ have microcephaly at birth, and only 6% have any type of physical abnormality by 12 months of age.² In addition, the guidelines stated that head circumference should be taken *within* 24 hours of birth; however, head circumference measurement is not accurate until at least 24 hours *after* birth due to head molding from the birthing process. After review of the evidence, the MOH in each country agreed to these changes, and a comprehensive list of suspected abnormalities and delays were added to the clinical description of CSaZ and the potential for microcephaly at birth was clarified.

Updates to the clinical management section centered around the need to emphasize the risk of CSaZ to all children born during times of active transmission. The key reason for this recommendation is based on the lack of reliable testing capabilities in the Eastern and Southern Caribbean, which results in identifying only babies with obvious signs (clinical findings) of CSaZ, or babies born to mothers with a history of perinatal fever and rash. Based on the data referenced above, the evidence shows that the majority of babies born during a time of active transmission will not show clinical findings at birth yet could develop signs and symptoms over the first several years of life. Therefore, the AAP recommended the clinical management protocol be divided into three sections—1) infants with clinical findings at birth, 2) infants without clinical findings at birth but whose mother had fever and rash during pregnancy, and 3) infants without clinical findings at birth and born to a mother without a history of fever and rash during pregnancy³. Infants with clinical findings at birth receive additional Zika-related diagnostics and should then be referred to routine well-child care and neurodevelopmental screening. Infants without clinical findings but born to a mother with history of fever and rash should receive some additional evaluation for hearing, vision, and neurological deformities. Infants without clinical findings or maternal history should be referred to routine-well child care and neurodevelopmental screening for ongoing monitoring.

To ensure appropriate neurodevelopmental surveillance at the facility level and to address the need for improved sensitivity and specificity in the existing child health record surveillance tool, the team of AAP experts, in close collaboration with USAID ASSIST technical team, revised the tool to align with international standards (using a review of evidence-based assessment tools), updated to differentiate red flag milestones by age (90% of children should achieve the milestone by that age) and normative milestones (50% of children should achieve the milestone by that age). The tool was updated to include more red flag milestones to reduce over-identification and referral, which was a key issue identified during the needs assessment. The tool was refined through an iterative process with each country's MOH and well-child care providers. Deliverables related to this activity include:

1. *Zika Virus infection guidelines for evaluation and management of infants* presented to Dominica, St. Kitts and Nevis, and St. Vincent and the Grenadines MOHs for final approval.
2. *Clinical Management Decision-Tree for Infants Born During Periods of Zika Transmission*
3. Updated *Neurodevelopmental Surveillance Tool* including evidence-based red-flag milestones and associated classification and treatment guide illustrating classification protocol based on developmental milestones of each child.
4. *Neurodevelopmental Surveillance Tool* caregiver take home card to support caregiver engagement and stimulation.
5. *Milestones in a Child's Development Booklet* job aid, which supports health workers to include counselling and caregiver engagement during each well-child visit to improve the neurodevelopmental surveillance process.

² Ibid

³ The systematization and some recommendations have been revised by ASSIST team to align with PAHO/WHO and CDC case definitions, though AAP's recommendation is to adjust based on context.

Newborn and well-child care providers trained to respond to expanded clinical needs of CSaZ

To build the skills of newborn and well-child care providers in each country, AAP provided four quarterly one-week, short-term technical assistance (STTA) trips including training providers in clinical skills and on-the-job mentorship. The content of each STTA built upon each other, culminating in sustainability planning with each MOH by the end of June 2019. A detailed itinerary of each TA trip and content delivered is below.

September 2018 TA
Update on Zika: What we have learned from 2016-2018 <ul style="list-style-type: none">• Epidemiological Update• Longer-term impacts of Zika and why microcephaly detection is not enough<ul style="list-style-type: none">◦ Defining Congenital Zika Syndrome• Clinical screenings and follow up care for Zika in newborns and young children
Essential Care for Every Baby (ECEB) Clinical Skills – Didactic <ul style="list-style-type: none">• 7 main interventions to prevent disease and assess<ul style="list-style-type: none">◦ Initiate breastfeeding, eye care, cord care, Vitamin K, examine for warning signs, temperature taking, and take weight• ECEB gray zone, leading into green zone and contrasting this with danger signs.• Additional screenings for all babies in the age of Zika• Special Needs of Small and Pre-Term Babies
ECEB – Hands on or Group-Based Discussion <ul style="list-style-type: none">• Practice exercise/case-based discussion in groups• Report out and discussion
Neurodevelopmental Surveillance and Well-Child Care <ul style="list-style-type: none">• Importance of well-child visits and neurodevelopmental screenings in high-risk babies (ALL babies are high-risk in Zika context)<ul style="list-style-type: none">◦ Surveillance vs. Screening◦ High-level introduction of December training on ASQ screening• Clinical presentations and diagnosis of developmental disorders in children• Introduction of surveillance tools and training to complete it• How to engage parents in surveillance process
Practicing Neurodevelopmental Surveillance <ul style="list-style-type: none">• Small group activity to practice screening with the tool• Discussion and report out
Site visits together with USAID ASSIST team
November/December 2018 TA
ECEB facility-based training <ul style="list-style-type: none">• Gray Zone: Care in the first 90 minutes• Green Zone: Care of the well baby• Yellow Zone: Care of the baby who is small or has an abnormal temperature or feeding problem

- Red Zone: Care of the baby with a danger sign or need for advanced care

Neurodevelopmental Surveillance in the Age of Zika

- Appropriate Developmental Milestones for Age
- Clinical presentations and diagnosis of developmental disorders in children
 - CSaZ delays
 - Autism
 - How to engage parents in the surveillance process
- Introduction to the updated surveillance tool
 - Child Health Record Form Surveillance tool
 - Overview of the form and how to complete it
 - How to classify children
- Hands on Practice: Using the surveillance tool
- Encouraging Stimulation and Delivering News on Abnormalities
- Referral and Follow-up Planning for Babies with Developmental Risks or Delays

Site visits together with USAID ASSIST team

February/March 2019 TA

ECEB Skills/Knowledge Lab – Hospital Based Staff

- Gray Zone: Care in the first 90 minutes
- Green Zone: Care of the well baby
- Yellow Zone: Care of the baby who is small or has an abnormal temperature or feeding problem
- Red Zone: Care of the baby with a danger sign or need for advanced care
- Concurrent training/coaching of/with novice Master Trainers
- Debrief with facilitators and becoming an ECEB Champion

Well-Baby Skills/Knowledge Lab – Clinic Based Staff

- Introduction to Becoming a Well-Child Champion
- Champion Skills
 - Delivering information and providing feedback to colleagues
 - Supporting strong provider/patient communication
 - Tips for ensuring ongoing learning
- Practicing being a Champion
- Well-Baby Champions: Defining your role
 - Implementation of the NDS tool
 - Quality of care
 - Sustaining and advancing the well-baby system beyond the project

Neurodevelopmental Surveillance Training Refresher

- Remembering Milestones by Age: Refresher & Introduction to the Milestones Booklet
 - Introduction on use and evolution
 - Discuss how the booklet can be used in conjunction with the NDS tool
 - Refresher of milestones by age
- NDS Tool Refresher
 - Refresh on key areas that were specific “trouble spots”

<ul style="list-style-type: none"> ▪ How to Define 'Red Flags' ▪ Determining Risk Factors ▪ Classification Tips ▪ Warning signs & appropriate follow-up • Autism: What you need to know <ul style="list-style-type: none"> ○ Identifying Autism Spectrum Disorder <ul style="list-style-type: none"> ▪ Understanding how Autism may differ from diagnosis with CZAS ○ Managing children with Autism <ul style="list-style-type: none"> ▪ How this may impact other areas of their care • Zika Clinical Care Roadmap and Referral Pathways: Ensuring the Health System is Prepared <ul style="list-style-type: none"> ○ Introduction to the Clinical Care Roadmap and refresher on referral pathways
May/June 2019 TA
<ul style="list-style-type: none"> • Follow-Up Focus Group Discussion with ECEB and NDS Mentors • NDS Tool Refresher with Updates • Introduction of Q-CHAT Autism Screener • Sustainability Planning discussions with Mentors, USAID ASSIST team and MOH

Deliverables related to this activity include:

1. *ECEB Parent Guide Insert* including instructions to parents to seek care if Zika-related concerns arise.
2. *ECEB in the Age of Zika Provider Guide Insert* includes additional points of intervention regarding screening for CZaS abnormalities
3. *Identifying Congenital Syndrome associated with Zika Through Essential Care for Every Baby* is an adapted ECEB Action Plan with additions related to identifying abnormalities related to CSaZ and emphasizing head circumference measurement and additional CZaS specific danger signs.

Country-specific Results

ANTIGUA AND BARBUDA

In order to sustain activities beyond the life of the project, AAP trained six Well-Child Champions and six ECEB Champions. Each set of Champions is charged with providing on-going training and mentorship around neurodevelopmental surveillance and essential newborn care, respectively, to their peers. This includes on-the-job training as well as formal refresher trainings.

After one year of training and mentorship, quality improvement indicator data was reviewed with the USAID ASSIST team and the MOH. The most frequently improved indicator was proper measurement and interpretation of head circumference. Neurodevelopmental surveillance using a revised NDS tool at every visit was also noted as an improved indicator by several facilities. Improvements may have been attributed to formal training of staff on obtaining accurate measurement and its importance in the context of Zika, consistent availability of measuring tapes and head circumference charts, and the introduction of the NDS tool which allowed for improved documentation of all core components of neurodevelopmental surveillance at each well-baby visit (including assessment of risk-factors and phenotypical abnormalities, measurement of microcephaly and skills, reflexes and speech milestones that could reflect the vision and hearing abnormalities known to be associated with Zika).

The least improved indicator at all health facilities was exclusive breast feeding at six months. Barriers to improving breastfeeding exclusivity were cultural practices, parents' and grandparents' attitudes, medical

complications, returning to work (associated with challenges in expressing breast milk and in exclusive breast milk consumption at day care or in family care), and confusion about the definition of exclusive breastfeeding as it relates to data collection.

Institutionalization of ECEB is ongoing. Champions and trainers complete chart reviews at the end of shifts to promote appropriate documentation. Improvements in documentation are also supported through the ongoing quality improvement (QI) efforts introduced by the USAID ASSIST team, including measurement of selected indicators at every well-baby visit to monitor the progress in improving neurodevelopmental surveillance, ongoing support by coaches to address gaps in quality of neurodevelopmental surveillance, correct and consistent documentation and reporting, and quarterly learning sessions to share and learn from experiences of health facility teams. Some Champions are conducting weekly trainings and QI efforts related to the use of tools and proper documentation at all clinics for which they are responsible. Most notably, ECEB has been institutionalized as a policy in the hospital.

DOMINICA

In order to sustain activities beyond the life of the project, AAP trained four Well-Child Champions and five ECEB Champions. Each set of Champions is charged with providing on-going training and mentorship around neurodevelopmental surveillance and essential newborn care, respectively, to their peers. This includes on-the-job training as well as formal refresher trainings.

After one year of training and mentorship, quality improvement indicator data was reviewed with the USAID ASSIST team and the MOH. Country-wide, the most improved indicator was proper measurement and interpretation of head circumference. This was attributed to formal training of staff, standardization of measuring tapes at hospitals and health facilities, introduction of the NDS tool and subsequent improved documentation, and improved staff attitudes.

The least improved indicators at most health facilities were exclusive breast feeding at six months and neurodevelopmental surveillance at every visit. Barriers to improving breastfeeding exclusivity were cultural practices, introduction of taro root, parents' and grandparents' attitudes, medical complications, returning to work, and confusion about the definition of exclusive breastfeeding as it relates to data collection. Barriers to neurodevelopmental surveillance included the NDS tool not being available at all health facilities, staff work overload, and lack of information about neonatal risk factors available from the hospital record.

Institutionalization of ECEB and well-child care/neurodevelopmental surveillance is ongoing. While no formal trainings on either ECEB or well-child care have taken place, Champions have informally disseminated information about ECEB skills and head circumference measurement and using the NDS tool.

ST. KITTS AND NEVIS

In order to sustain activities beyond the life of the project, AAP trained six Well-Child Champions and three ECEB Champions. Each set of Champions is charged with providing on-going training and mentorship around neurodevelopmental surveillance and essential newborn care, respectively, to their peers. This includes on-the-job training as well as formal refresher trainings.

After one year of training and mentorship, quality improvement indicator data were reviewed with the USAID ASSIST team and the MOH. All but one health facility showed greatest improvement in their measurement and documentation of head circumference. Other significant improvements were made in the documentation of skills and reflexes for specific age groups. The least improved indicator across all health centers was exclusive breastfeeding at six months.

Efforts to institutionalize ECEB include incorporating the training into Baby Friendly Hospital training and sensitization. This training is required of all hospital staff, even nonmedical personnel such as housekeeping and security, and it is adapted as appropriate to the staff member's role. A tangible result of this facility-wide training is the ordering of Nifty Feeding Cups by the supplies manager, and cup-feeding has been adopted with patient care. Additionally, nurses have implemented interventions to improve skin-to-skin practices, which has led to improvement in multiple indicators (breastfeeding initiation and jaundice).

ST. VINCENT AND THE GRENADINES

In order to sustain activities beyond the life of the project, AAP trained two Well-Child Champions and seven ECEB Champions. Each set of Champions is charged with providing on-going training and mentorship around neurodevelopmental surveillance and essential newborn care, respectively, to their peers. This includes on-the-job training as well as formal refresher trainings.

The MOH has committed to disseminating 4,000 copies of the NDS tool to be incorporated in the Child Health Passport.

Regarding institutionalization of ECEB, improvements in skin-to-skin care was anecdotally reported by ECEB Champions. In addition to an increase of observations of the practice, the length of skin-to-skin contact for one hour has become common practice in the hospitals. As a result, more babies have normal temperatures after birth. Emphasizing skin-to-skin care also naturally led to more women breastfeeding earlier. Anecdotally, ECEB Champions believe more fetal macrosomia babies had stable blood sugars and wondered if this was due to more skin-to-skin care and encouragement of immediate breastfeeding.

At the health facility level, expectations about skin-to-skin care and breastfeeding are now discussed during antenatal care visits. Additional content on breastfeeding was provided by AAP, including videos. Families were encouraged to bring blankets for skin-to-skin care, and breastfeeding was discussed. This will likely help future mother manage their expectations about postpartum care and be a more active and engaged participant in their care.

3 Recommendations

In order for the MOH in each country to continue the gains in implementation made since August 2018 to improve essential newborn care neurodevelopmental surveillance and overall improved care for babies and children with delays in the age of Zika, the AAP recommends the following:

- All MOHs without updated pediatric guidelines for management of Zika should review the guidelines developed by AAP and the USAID ASSIST team and adapt and finalize them for implementation in their country. Finalization should include development of a dissemination plan, such as a formal scientific launch attended by all key public and private stakeholders. Additionally, each MOH should plan to update the guidelines when major changes in availability of diagnostics, particularly reliable laboratory testing for Zika, or if and when major changes in identification of clinical management are recommended by global partners.
- In order to ensure full institutionalization of ECEB, MOHs must commit to supporting ECEB Champions in hosting cascade and refresher trainings. This includes committing to providing time for Champions and participants to conduct and attend refresher trainings, making all training materials routinely available to Champions and Trainers, and sharing successes around improved quality improvement indicators.
- Similarly, for Well-Child Care Champions, MOHs must support ongoing coordination of the NDS Tool implementation by making tools and additional job aids available to all health facilities as soon as possible and eventually include them in the revised child health record. The successes already achieved around head circumference measurement and neurodevelopmental

surveillance show the possible long-term impact that improved record-keeping and documentation can have on identification of children with possible developmental delays.

- Each MOH should consider ongoing monitoring of referrals for children with possible developmental delays to referral facilities. While referral pathways were mapped during the scope of the project, ongoing monitoring and problem solving around availability of needed referrals will be a need as the NDS tool is fully rolled out.
- Each MOH should strengthen in-service, pre-service, and ongoing supervision around essential newborn care, with an emphasis on exclusive breastfeeding. This area was across the board low in all countries, and despite its importance to essential care, continued to face the most push back from both providers and caregivers.

In addition, the below recommendations are specific to each country based on gaps and opportunities identified over the 12 months of the project.

Antigua

- Well-child Champions currently do not have access to breastfeeding ECEB supplies on which to train/practice. The MOH should consider cross-training of ECEB and Well-Child Champions to support a continuum of care around exclusive breastfeeding.
- In order to support ongoing formal trainings, the MOH should provide both ECEB and Well-child Champions clear expectations as far as whom to train (for example, all mother-baby nurses and/or clinic nurses who perform well-baby exams) and by what deadline on an annual basis.
- Inclusion of head circumference growth chart in the child health record would help with proper classification and monitoring of baby's growth and development.
- A job aid listing the key components of a well-child check, including the new NDS tool, to ensure it is completed at every visit.

Dominica

- Concerns were raised by Well-child Champions that lack of training of the District Medical Officers in the updated NDS tool may lead to push-back and refusal to provide referrals based on the nurse's recommendation. The MOH should bring all District Medical Officers and Senior Nursing Officers together for a brief update/refresher on NDS and introduction to the NDS Tool and newly developed referral pathways to ensure a continuum of care.

St. Kitts and Nevis

- As the Ministry of Education is highly involved in neurodevelopmental surveillance and assessment of school-age children, the MOH and Ministry of Education should identify a reporting structure to ensure continuity across well-child care and school-age care, as well as consistent referrals and follow-up care.

St. Vincent and the Grenadines

- The MOH should follow up with both ECEB and Well-Child Champions to ensure plans are developed to cascade the respective materials and support continuous low-dose, high-frequency trainings. Long gaps between trainings will decrease skill retention, mitigating the possible long-term impacts of the Champion/Training of Trainer model.
- The MOH and ECEB mentors must better coordinate around planning of trainings and receiving ECEB training materials, as materials are currently housed in one location. A training schedule agreed upon by both parties would help alleviate some of these issues.

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University Research Co., LLC
5404 Wisconsin Avenue, Suite 800
Chevy Chase, MD 20815

Tel: (301) 654-8338

Fax: (301) 941-8427

www.usaidassist.org