



USAID
FROM THE AMERICAN PEOPLE

USAID
ASSIST PROJECT
*Applying Science to Strengthen
and Improve Systems*

TECHNICAL REPORT

Gender Issues Influencing Zika Response in Antigua

DECEMBER 2019

This technical report was prepared by University Research Co., LLC (URC) for review by the United States Agency for International Development (USAID) and authored by Morgan Mickle, Kelly Dale, and Taroub Harb Faramand of WI-HER, LLC and Alexandrina Wong of Women Against Rape Antigua and Barbuda under the USAID Applying Science to Strengthen and Improve Systems (ASSIST) Project. The work of the USAID ASSIST Project to improve Zika-related health services is made possible by the generous support of the American people through USAID.

TECHNICAL REPORT

Gender Issues Influencing Zika Response in Antigua

DECEMBER 2019

Morgan Mickle, WI-HER, LLC

Kelly Dale, WI-HER, LLC

Alexandrina Wong, Women Against Rape Antigua and Barbuda

Dr. Taroub Harb Faramand, WI-HER, LLC

DISCLAIMER

The contents of this report are the sole responsibility of University Research Co., LLC (URC) and do not necessarily reflect the views of the United States Agency for International Development or the United States Government.

Acknowledgements

This report was written by Morgan Mickle, Kelly Dale, and Taroub Faramand of WI-HER, LLC, and Alexandrina Wong of Women Against Rape Antigua and Barbuda (WAR) for the USAID Applying Science to Strengthen and Improve Systems (ASSIST) Project, which is funded by the American people through the United States Agency for International Development (USAID) Bureau for Global Health, Office of Health Systems.

The authors would like to thank Dr. Shivon Belle-Jarvis, Head of the Pediatric Department at Mount St. John's Medical Center in Antigua, for her role as focal point for this analysis and the following health providers who facilitated coordination at their respective facilities: Nurse Richardson (Grays Farm), Nurse Williams (All Saints), Nurse Samuel (Browne's Avenue), Nurse Gregory (MSJMC), and Matron Juliet Delabastide (Care Project). The authors would also like to thank WI-HER staff Allison Annette Foster for her support of this gender analysis and Dr. Tamar Chitashvili and Salwan Hager of URC for their technical reviews at all stages of implementation of this gender analysis.

The USAID ASSIST Project is managed by University Research Co., LLC (URC) under the terms of Cooperative Agreement Number AID-OAA-A-12-00101. URC's global partners for Zika support under USAID ASSIST include: the American Academy of Pediatrics, FHI 360; Institute for Health care Improvement; and WI-HER, LLC. For more information on the work of the USAID ASSIST Project, please visit www.usaidassist.org or write assist-info@urc-chs.com. For more information on integrating gender in Zika care, please contact tfaramand@wi-her.org.

Recommended citation

Mickle M, Dale K, Wong, A, Faramand TH. 2019. Gender Issues Influencing Zika Response in Antigua. *Technical Report*. Published by the USAID ASSIST Project. Chevy Chase, MD: University Research Co., LLC (URC).

TABLE OF CONTENTS

List of Tables and Figures	i
Acronyms	ii
Executive Summary	iii
I. Background	1
II. Introduction	2
III. Objectives	4
IV. Methodology	4
A. Desk Review	5
B. Tool Development.....	5
C. Selection of Sites	5
D. Sample Size and Limitations	6
E. Participant Selection	7
F. Data Collection.....	8
G. Data Analysis	8
V. Gender Analysis Findings and Discussion	8
A. Zika Knowledge and Prevalence	8
B. Family Dynamics and Caretaking.....	9
C. Disability and Social Inclusion	15
D. Additional Takeaways.....	17
VI. Recommendations and Way Forward	21
VII. Conclusion.....	26
References.....	27
Appendices	28
Appendix 1: Focus Group Discussion Guide.....	28
Appendix 2: Key Informant Interview Guide	30

List of Tables and Figures

Table 1. Summary of Zika cases 2015-2019	3
Table 2. Number of focus groups and key informants reached	5
Table 3. Focus group discussion characteristics	7
Table 4. Care seeker responses to “what makes a ‘good’ father and a ‘good’ mother?”	10
Figure 1. Map of data collection sites	6
Figure 2. Focus group participants by sex.....	7
Figure 3. Key informant interviews by sex	7

Acronyms

ANC	Antenatal Care
ASSIST	USAID Applying Science to Strengthen and Improve Systems Project
CARPHA	Caribbean Public Health Agency
CDC	United States Centers for Disease Control and Prevention
CSaZ	Congenital Syndrome associated with Zika
FGD	Focus Group Discussion
FP	Family Planning
GBC	Guillain-Barre Syndrome
GBV	Gender-Based Violence
KII	Key Informant Interview
MOH	Ministry of Health, Wellness and the Environment
NCH	Newborn and Child Health
PAHO	Pan American Health Organization
PWD	Person with Disabilities
STI	Sexually Transmitted Infection
URC	University Research Co., LLC
USAID	United States Agency for International Development
WAR	Women Against Rape Antigua and Barbuda
WHO	World Health Organization

EXECUTIVE SUMMARY

The USAID Applying Science to Strengthen and Improve Systems Project (ASSIST) has worked globally since 2012 to build the capacity of host country service delivery organizations to improve health and family services. ASSIST has worked in Latin America and the Caribbean since 2016 supporting 13 countries as part of USAID's emergency response to Zika to improve the capacity of Zika-related health services and to deliver consistent, evidence-based, respectful, high-quality care. ASSIST-sponsored efforts in Antigua commenced in 2018 to support local partners to screen, identify, and provide recommended care to children and families potentially affected by Zika, and strengthen other Zika-related services such as well-baby and well-child care, early childhood development, and psychosocial support systems. WI-HER, LLC, expert gender partner on the USAID ASSIST Project, provides technical leadership and capacity building for improved services and systems using a gender lens.

To better understand the real-time situation of Zika-related health services for women, men, couples, and families, project stakeholders commissioned this gender analysis to look at existing services, challenges, and opportunities. The analysis, conducted in two ASSIST-supported parishes in Antigua, includes information gathering from patients and health care providers in five health facilities. A total of 70 persons shared their experiences and perceptions related to Zika knowledge and awareness, family economics and decision-making, well-baby care and long-term caretaking, and the impacts of disability on families. Key findings include:

- Care seekers are aware of Zika transmission by mosquitos but not with regards to sexual transmission, and misinformation about Zika symptoms and transmission exist;
- Both parents are involved in child care in dual-parent households, though primary responsibilities often fall to the mother;
- Perceptions of masculinities are not changing for men's own health, but changing for male involvement in their partner's health;
- Maternity and paternity policies can impact parental-child bonding and care roles;
- There is a discrepancy between what community members and family members of persons with disabilities perceive with regards to discrimination and stigma;
- Caring for children with disabilities can create additional emotional, financial, and physical stressors for families;
- The wider public feels that persons with disabilities are at greater risk of violence;
- Services for persons with disabilities are limited;
- Socio-cultural shifts are present in the country that affect care and support systems;
- While condoms are used, most pregnancies are not planned, and contraception is seen as ineffective;
- Barriers to quality and equitable care exist and can be improved upon.

Using these findings, nine recommendations were formulated to improve family health care, services for persons with disabilities, and generally the health system in Antigua. These recommendations should guide the MOH in preparing the health system to handle future disease outbreaks and to continually provide quality care for the people of Antigua and Barbuda. The recommendations focus on improving public education and awareness around key themes, promoting male engagement in well-baby care, increasing counselling opportunities and psychosocial support, improving coordination with other ministries/departments for public health outreach and social support, creating a web-based training platform for providers and staff or other efficient mechanisms to build and sustain capacity in sensitivity and cultural diversity; working with persons with disabilities and their families, including psychosocial support, gender awareness and gender-based violence and abuse; updating outdated policies and implementation tools based on input from community members and providers and make these tools more

accessible for use, improving referral systems, strengthen systems to support continuous quality improvement, and improve accessibility of related services.

I. BACKGROUND

The USAID Applying Science to Strengthen and Improve Systems Project (ASSIST) has worked globally since 2012 to improve the quality and outcomes of health care and other services by enabling host country providers and managers to apply quality improvement methods. ASSIST seeks to build the capacity of host country service delivery organizations in USAID-assisted countries to improve the effectiveness, efficiency, client-centeredness, safety, accessibility, and equity of the health and family services they provide.

As part of USAID's emergency response to Zika, ASSIST has been implementing health systems strengthening efforts in Latin America and the Caribbean since 2016. ASSIST works to improve the capacity of Zika-related health services to deliver consistent, evidence-based, respectful, high-quality care with a focus on pregnant women, newborns, and women and girls of reproductive age.

As part of the Zika response, ASSIST achieves improved capacity by supporting Ministries of Health and Social Security Institutions in four Eastern and Southern Caribbean countries of St. Vincent and the Grenadines, St. Kitts and Nevis, Antigua, and Dominica to:

- Improve clinical screening for microcephaly and other manifestations of congenital syndrome associated with the Zika virus in newborns and increase the number and proportion of affected infants receiving recommended care women and families affected by Zika; and
- Improve clinical screening for signs and symptoms of potential Zika infections during pregnancy and implementation of recommended care;
- Strengthen the provision of quality psycho-emotional support services for women and families affected by Zika.

Since 2018, the USAID ASSIST Project has been working in Antigua to improve the capacity of health service providers under the Ministry of Health to deliver consistent, evidence-based, respectful, high-quality Zika-related care. Implementing activities are focused on improving service delivery in newborn and child health (NCH) and family health services, supporting improvement in the care of newborns and children potentially affected by Zika, and strengthening health systems in well-baby clinics and in early childhood development programs in all functional health facilities by providing technical assistance to caregivers and service providers in these service delivery areas.

WI-HER, LLC, a women-owned small business and international development consulting firm, provides technical leadership on integrating gender into the Zika emergency response under the ASSIST Project. To integrate gender, WI-HER developed an innovative, results-oriented approach that draws directly from the science of quality improvement, called *iDARE*, which is an acronym for Identify, Design, Apply/Assess, Record, Expand (WI-HER, LLC, undated).

The first two steps of the *iDARE* approach – Identify and Design – ensure that contextually appropriate interventions are implemented. These steps have a gender perspective that takes the different needs and behaviors of women, men, girls, and boys into consideration. The final three steps – Apply/Assess, Record, and Expand – ensure that this approach is constantly examined, evaluated, and adjusted to ensure continued effectiveness and improved development and humanitarian outcomes. The *iDARE* approach has been proven effective at multiple levels and across 35 countries in Africa, Asia, Eastern Europe, Latin America, and the Middle East.

To improve the effectiveness of the program in reaching women and vulnerable populations, WI-HER conducted a gender analysis of the delivery of services in health facilities and sociocultural factors that create barriers to Zika prevention and care. Along with an extensive desk review, the analysis was comprised of 5 Focus Group Discussions (FGDs) (antenatal couples, women of reproductive age, parents of children under 5, parents of children with disabilities, and high-risk antenatal couples), and 13 key

informant interviews (KIIs) with health providers and professionals (community health aides, district nurse midwives, doctors, registered nurses, a registered nurse midwife, and a social worker).

The gender analysis revealed issues that affect the quality and effectiveness of antenatal care, well-baby care for children under 5 years old, and long-term childcare within family health which will be explained in detail throughout this report. These issues need to be addressed as part of quality improvement of the Zika response in health facilities and through community-based activities to reach populations with limited access to health facilities. It is critical to ensure that women, men, girls, and boys can take the steps necessary to prevent and respond to Zika through access to comprehensive family planning services and education. Additionally, findings from this analysis support the notion that integrating gender cannot only help improve Zika emergency response programming, but also leverage improvements in related health areas such as maternal child health/antenatal care, family planning, psychosocial support, and quality care in general so that health systems are strengthened for any future resurgence or new health epidemics.

II. INTRODUCTION

Zika is a flavivirus transmitted by the *Aedes* species mosquito that was first discovered in Uganda in 1947. Between the 1960s and 1980s, human infections were found across Africa and Asia. In 2007, the first large outbreak of the infection was reported in the Federated States of Micronesia. As the infection spread across the Pacific researchers started to link it to other health challenges such as Guillain-Barre syndrome (GBS), an illness affecting the nervous system that can result in muscles weakness and paralysis. In 2015, Zika virus infection made its way to South America arriving first in Brazil in May. By July, Brazilian health authorities reported an association between Zika and GBS, and by October the infection was linked with another significant health challenge - microcephaly, a congenital birth defect whereby a baby's head is smaller than expected when compared to babies of the same age and sex. (Microcephaly has also been associated with other birth defects and neurological conditions in children and adults.) Zika virus infection quickly swept across the Latin America and Caribbean region. By February 2016, the World Health Organization declared Zika virus infection a Public Health Emergency of International Concern (PHEIC) due to its associations with microcephaly and other neurological disorders.

The first autochthonous case of Zika transmission in Antigua and Barbuda was reported in July (Epidemiologic Week 30) of 2016 (PAHO/WHO 2017). According to statistics reported to the Pan American Health Organization (PAHO) and the World Health Organization (WHO), between arrival of the virus to the region in 2015 and January 2018, there were 25 cases of confirmed Zika virus infection in Antigua and Barbuda. No data is publicly available on PAHO/WHO's platform after January 4, 2018 (PAHO/WHO 2018a). PAHO/WHO's last epidemiological report for Antigua and Barbuda detailed that as of July 2017 there were 16 reported and suspected cases of Zika among pregnant women of which 6 were confirmed. (The last confirmed case of Zika virus infection was November 2016.) As of September 2017, no cases of Zika virus were associated with Guillain-Barre Syndrome, Congenital Syndrome associated with Zika (CSaZ), or death. In October 2018, the Caribbean Public Health Agency (CARPHA) released data giving evidence that Zika virus transmission in the Caribbean had been interrupted for over 12 months or was at undetectable levels (CARPHA 2018). Soon after, the WHO removed its classification scheme which had previously identified active transmission in many Caribbean territories (PAHO/WHO 2018b).

Table 1. Summary of Zika cases 2015-2019

	Antigua & Barbuda	Dominica	St. Kitts & Nevis	St. Vincent & the Grenadines
Zika first confirmed	July 2016	March 2016	September 2016	February 2016
Cumulative Suspected Cases 2015-2018	540	1154	554	508
Cumulative Confirmed Cases 2015-2018	25	79	33	83
Reported CSZ 2015-2018	0	0	0	0

Sources: PAHO/WHO Cumulative Cases 2015-2018, as of January 4, 2018

Table 1 note: During an ASSIST scoping visit in July 2018 the Antigua and Barbuda Ministry of Health reported the total suspected cases at 552, confirmed cases at 28, and CSZ at 2.

While CARPHA has reported virtually no active Zika transmission and the WHO has discontinued their classification system, prevention efforts should be maintained in health facilities to avoid any potential resurgence, particularly given the size of the island and frequent foreign visitors. The U.S. Centers for Disease Control and Prevention (CDC) identifies multiple Zika transmission pathways (CDC 2018):

- Through the bite of an infected Aedes mosquito;
- From a pregnant woman to her unborn child during pregnancy or around the time of birth. Zika transmission during pregnancy can cause CSaZ, which can include microcephaly and a range of other fetal brain defects and developmental delays;
- Through the consumption of breast milk, though it is important to clarify that there have been no reports of CSaZ in babies resulting from breast milk from a woman with Zika virus infection;
- Through sex (vaginal, anal, and likely oral), from a person who has Zika to his or her partners;
- Through blood transfusion;
- Through exposure to the virus in a laboratory and health care setting.

Although Zika did not spread in Antigua to a serious degree, it only took a year for the regional outbreak to impact the island. This suggests that vigilance is an essential tool in preparing for future public health emergencies and that health systems must be strengthened to respond quickly to related or similar outbreaks such as dengue and chikungunya. Regardless of the number of cases, Zika response efforts must be continued and the long-term impacts of the virus (initial epidemic) on populations not overlooked. As more research is being conducted we are learning that some babies with possible Zika infection during pregnancy may look healthy at birth but may develop long-term health challenges as they grow (CDC 2019; Huang 2019). Due to the challenges in identifying Zika and babies affected by the virus, it is necessary to prepare for families who may have been missed and who will need screening and referral services in the future. Children affected by the developmental disabilities caused by the Zika virus, called Congenital Syndrome associated with Zika (CSaZ) will need long-term access to health and specialized services such as early childhood stimulation. Families will also need financial and psycho-social support

to meet regular well-child care, provide any additional care needs, and address emotional issues. To respond to these needs most effectively, and to design initiatives that will best help families protect themselves from Zika, Zika response and prevention programs will need to better understand how social roles and expectations can affect health-seeking behaviors and integrate gender-sensitive interventions that address the variances of needs and behaviors of women, men, boys, and girls. This understanding and capacity to integrate gender into primary health care services not only prepares the system for Zika response, but also improves maternal, newborn, and child health (MNCH) care, and leads to sustainable system improvements that save lives and enrich the health and well-being of mothers, children, and families.

This gender analysis pulls from community member and health provider perspectives to illustrate important factors to consider in Zika prevention and response initiatives.

III. OBJECTIVES

The overall objective of this gender analysis was to identify key gender-related barriers and gaps that influence newborn health services and well-baby care systems with a focus on babies and families potentially affected by Zika. The team's analysis identified challenges, best practices, approaches, and opportunities related to family dynamics and well-baby care in the context of Zika in Antigua, in order to make recommendations to improve public awareness related to stigma and disabilities, engage men across family and personal health services, increase counselling and psychosocial support opportunities for families, improve coordination across ministries, maximize innovative training platforms for health providers, improve outreach tools to meet a wider client base, strengthen referral systems, improve the quality of care, and address challenges families face in accessing facilities.

IV. METHODOLOGY

To achieve the objectives, the three-person analysis team used a mixed methods approach to conduct the gender analysis. Mixed methods analyses integrate qualitative and quantitative approaches to data collection, data review, and interpretation. The team chose a mixed methods approach because it: (1) strengthens the reliability of data and validity of findings and recommendations by triangulating methods and data sources; (2) provides greater breadth and depth of understanding of the gender-based influences of health outcomes; and (3) integrates findings to provide maximum improvement for designed and implemented activities.

The team conducted: (1) an in-depth desk review on gender issues in the context of Zika emergency response programming in the Eastern and Southern Caribbean region including Antigua; (2) key informant interviews (KIIs) with 13 health providers and professionals in Antigua; and (3) 5 focus group discussions (FGDs) with a total of 57 participants in Antigua. A total of 70 participants in Antigua were reached through this analysis exercise. These data were analyzed independently and compared across data collection modalities to triangulate the results. A Ministry of Health focal person worked in partnership with the analysis team to coordinate sites and logistics as described in the following sections.

Table 2. Number of focus groups and key informants reached

Facility Name	Facility Type	# of focus groups	# of focus group participants	# of key informant interviews	Total # of people (FGD and KII)
Grays Farm	Community Health Center	1	9	3	12
All Saints	Community Health Center	1	10	3	13
Browne's Avenue	Community Health Center	1	8	3	11
Care Project	Govt.-supported Center for Persons with Disabilities	1	12	0	12
Mt. St. John's	National Hospital	1	18	4	22
TOTAL		5	57	13	70

Table 2 Note: At Care Project there were 10 parents in the focus group and 2 additional persons present. For more detail see Data Collection section below.

A. Desk Review

The team conducted an extensive desk review on gender, disability, well-baby care, and Zika for all four Eastern and Southern Caribbean Islands where ASSIST works (Antigua, Dominica, St. Kitts and Nevis, and St. Vincent and the Grenadines) (Mickle et al. 2019). The team gathered available sex-disaggregated, qualitative, and quantitative data, and relevant background information. The search parameters were intentionally broad to account for the dearth of comparable country-level data in the Caribbean region. Materials reviewed include peer-reviewed publications, policy papers, gender analyses, case studies, literature reviews, publicly available data, project evaluations, government and international policies and documents, program reports, grey literature, and other materials released within the past 15 years.

Antigua-specific findings from this desk review were used to inform tool development (FGD and KII guides) and are included in this analysis.

B. Tool Development

FGD and KII guides (see **Appendix 1** and **2**) were developed based on the objectives proposed by the ASSIST team and supplemented with findings from the desk review. All tools were shared and approved by the Antigua and Barbuda Ministry of Health and the Environment and received IRB approval from the Ministry of Health.

The FGD guide was piloted at Grays Farm Health Center with a group of antenatal couples, and the KII guide was piloted with a community health aide. The guides were then improved upon and applied to all subsequent FGDs and KIIs. No substantive changes were made as a result of the pilots, and therefore the results of the pilot FGDs and KIIs were included in the final analysis. Changes included a re-ordering of questions, re-wording to avoid repetition, and new questions regarding demographic background of participants, contraceptive use including condom use and decision-making, marriage trends, and experiences with confidentiality in the health facility.

C. Selection of Sites

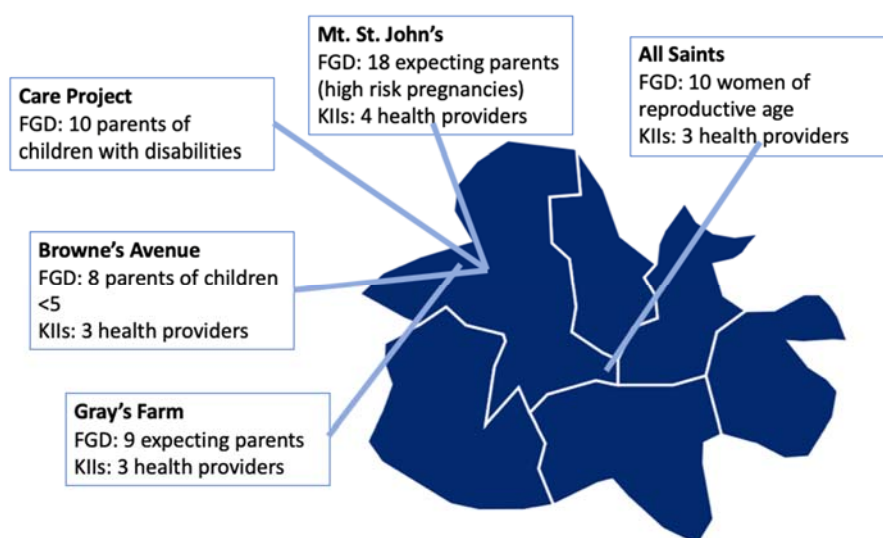
For the gender analysis, the MOH focal point coordinated with ASSIST-supported quality improvement coaches (a select group of health providers tasked with overseeing quality improvement activities at their health facilities) and facilities to select four (4) health facilities (3 community-based health centers and the national hospital) to conduct FGDs and KIIs. This was done on the basis of convenience and participation in the USAID ASSIST Project. The analysis also included a FGD at one additional government-funded facility, not covered under the ASSIST Project, to engage parents and health professionals supporting children with disabilities. This facility was selected by the MOH focal point in coordination with that facility's leadership. All selected sites were located near the capital city. The process of selection used to identify FGD and KII participants is described below under "Participant Selection".

The selected sites, shown in **Figure 1**, were:

- Grays Farm Health Centre
- All Saints Health Centre
- Browne’s Avenue Health Centre
- Care Project – the only government-supported program for persons with disabilities; the facility houses residents as well as day-care clients.
- Mount St. John’s Medical Centre (MSJMC)

While all sites were in St. John’s and St. Peter’s parishes, the respondents came from several parishes throughout Antigua. As such, these sites allowed for different perspectives from across parishes and at differing levels of the health system (health centers and a referral hospital).

Figure 1. Map of data collection sites



D. Sample Size and Limitations

Sample size was calculated based on data saturation estimation when repetition and redundancy are observed in the data. We determined that one (1) FGDs per site, with 10-12 participants each, would be sufficient to elicit relevant variation in the themes of interest. For KIIs, we determined that interviewing one to two (1-2) health providers, per site would be sufficient to gather diverse perspectives.

There were several limitations to the sample. First, not all FGDs had the desired number of participants—two groups had fewer than 10 participants and one had more than 12. Furthermore, due to the convenience sampling approach, the sample may not be representative of the entire Antiguan population. For example, the men in the high-risk pregnancy group were all selected when they attended an ANC visit with their partners, which makes the sample itself biased towards persons who are highly engaged in health services. Similarly, women and men from the health center FGDs are more representative of those who seek health services than those who do not, and as will be explained below, they represented a certain social class. Selection bias may also be a limitation as facility nurses who worked at the centers chose the participants and may be somewhat familiar with patients who attended the FGDs. Finally, the parents of children with disabilities have children at the Care Project, meaning they are likely more aware of services than parents who do not access such services for their children with disabilities. Therefore, while findings from the FGDs are enlightening and reflect real opinions, they cannot necessarily be extrapolated to the entire population.

E. Participant Selection

The WI-HER team and MOH counterparts selected target FGD groups based on programmatic goals. The target groups included antenatal couples, women of reproductive age, parents of children under 5, parents of children with disabilities, and high-risk antenatal couples. The distribution of focus group participants by sex is shown in **Figure 2**. Parents with children under 5 were targeted specifically for focus groups because these mothers would have been pregnant during the Zika epidemic. All participants were over the age of 18 years old. Participants were representative of different parishes in Antigua. At health facilities, a nurse selected FGD participants through convenience sampling, extending invitations to interested participants or to clients in the waiting room at the facility. Pregnant women and male partners of pregnant women (high-risk/antenatal couples) were invited to participate in the FGDs before/after their antenatal care appointments, and women of reproductive age, parents of children under 5, and parents of children with disabilities were invited by the respective facility staff. **Table 3** shows the characteristics of focus group participants by health facility. Any participants approached in the waiting rooms were asked if they were interested in participating and informed that their participation would not conflict in receiving the health service they came for.

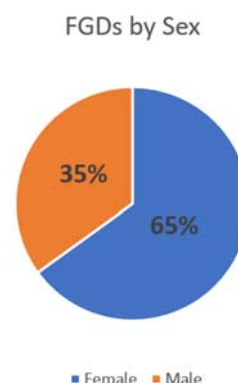


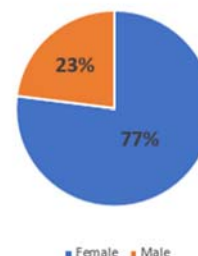
Table 3. Focus group discussion characteristics

Health Facility	Group Type	# of focus group participants	Age Range
Grays Farm	Antenatal Couples	9	22-49
All Saints	Women of Reproductive Age	10	18-35
Browne's Avenue	Parents of Children under 5	8	25-42
Care Project	Parents of Children with Disabilities	10	23-61
Mt. St. John's	Antenatal Couples (high risk pregnancies)	18	22-42

	Females	Males	# of participants with children	# of participants with children 5 years and younger	# of participants with children born between 2016 and 2017	# of female participants currently pregnant	# of participants non-Antiguans
Grays Farm	5	4	8	3	0	5	2
All Saints	10	0	6	4	1	0	4
Browne's Avenue	6	2	8	5	6	0	0
Care Project	6	4	10	4	2	0	0
Mt. St. John's	9	9	8	6	2	9	7
TOTAL	36	19	40	22	11	14	13

All participants were health providers and professionals working in newborn and child care for children under 5 (providing immediate postnatal care in hospitals and well-baby care in health centers) at the health facilities where FGDs were conducted. The distribution of key informant interview participants by sex is shown in **Figure 3**. The 13 participants included:

- Community Health Aide (4)
- District Nurse Midwife (2)
- Doctor (3) (including 2 Pediatricians)
- Registered Nurse (2)
- Registered Nurse Midwife (1)
- Social Worker (1)



F. Data Collection

From May 27-31, 2019 the data collection team conducted 5 FGDs and 13 KIIs in Antigua. Data collection team members were experienced qualitative researchers and were familiar with Zika and health systems in Antigua. Focus group participants provided written and oral informed consent before the beginning of each discussion and health providers, and professionals provided written consent prior to interviews. Participants were also assigned a unique identifier so that their identities remained anonymous. Each participant was given a copy of the consent form for their records. One member of the data collection team took notes during the FGDs, and KIIs and FGDs were audio recorded.

The team used a structured FGD guide, exploring general knowledge about Zika before asking questions about Zika knowledge and awareness, family economics and decision-making, well-baby care and long-term caretaking, and the impacts of disability on families.

FGD data collection took place in counseling rooms, an all-purpose room, a chapel, and a meeting space at each facility. All rooms were private with only facilitators and participants present so participants could speak freely. At the Care Project, a doctor and the matron of the facility were also included in the FGD to provide context to some of the services and policies available to families of children with disabilities. FGD duration ranged from forty-seven minutes to an hour and thirty-one minutes. All FGDs were conducted in English.

The KIIs also used a structured guide focused on Zika knowledge and awareness, family economics and decision-making, well-baby care and long-term caretaking, and the impacts of disability on families. KIIs were conducted in the same space as the focus group (not at the same time) or in private offices and lasted 45 minutes to an hour and 30 minutes. All KIIs were conducted in English.

G. Data Analysis

The three-person team that collected and analyzed the data was familiar with Zika and the Antiguan context. The team included a Registered Nurse with years of experience as a practitioner in the Antigua health system and as a professional specializing in gender issues. Participation of a local partner familiar with the culture and health system was key to the research and analysis. The written data was analyzed by the three coders who reviewed themes daily, and all themes after completing FGDs and KIIs. Aligning themes were more thoroughly examined to determine patterns of information, quantitative information that support qualitative findings, and to capture key quotations across participants groups to enhance the overall evidence and learning.

V. GENDER ANALYSIS FINDINGS AND DISCUSSION

A. Zika Knowledge and Prevalence

Our findings revealed that 100% of participants had heard of Zika virus and identified that the virus was transmitted by mosquitos. However, only community health aides in focus groups and health providers and professionals in key informant interviews expressed awareness of sexual transmission of Zika virus. Some persons knew that Zika virus could cause harm to babies; malformations and a big or small head were identified as examples. When probed about mitigating Zika, participants identified methods for vector control including using mosquito nets and repellent, cleaning up stagnant water and covering water containers, and wearing long sleeve clothing.

Generally, participants learned about Zika from their health centers, in brochures, on TV, on the radio, through news outlets, in school, and searching on the internet. One health provider also mentioned sources such as the CDC, CARPHA, PAHO, and the USAID ASSIST Project. Health providers mentioned that it is important to discuss Zika during well-baby clinics, and one provider noted that knowing about Zika is especially important for pregnant women. However, at least one care seeker stated that both men and women should be equally concerned with Zika as the virus itself isn't gender specific and the

mosquito doesn't differentiate between biting a man and a woman. One health provider agreed that including both partners in discussion during ANC where possible would most beneficial.

"At the end of the day it's a birth defect so that affects both partners." (Parent of PWD)

"We talk to pregnant women and we should talk to male partners if they come, but they don't usually come." (Female health provider)

Despite the wide variety of information sources, there exists misinformation about Zika virus around symptoms and modes of transmission. One person mentioned that Zika causes a person's nose to bleed. Other individual responses were that Zika is an airborne disease, that it is passed through saliva, that it's very contagious, and that it's deadly. This misinformation has the potential to impact how people perceive or misperceive Zika and other diseases and could impact health-seeking behaviors and treatment. For example, if a person thinks their fever is related to a common cold, for example, but is actually related to Zika they might not seek the necessary care and treatment.

"I believe children will have to be isolated from the rest of the household to prevent others from getting it." (Female health care seeker)

Of the 57 care seekers consulted in this analysis, no one knew anyone with or affected by Zika virus. Among the 13 health providers, only two (2) had come across Zika and Zika-related cases in their work. One of the two providers knew of cases of Zika in both adults and children, including a pregnant woman, advised on Zika, and supported one patient during their pregnancy. For the known cases, the provider mentioned that the children who were exposed in utero are currently being followed and appear to be meeting their development milestones; though they are doing well, they are considered suspected cases. The same provider also noted that some cases are more difficult to draw a direct link as the child was born in the right time frame and exhibits signs of microcephaly, but that the time the parents brought the child to a health facility was outside of the window for detection. While the number of known and reported cases of Zika virus and babies affected by Zika virus is low across the country, more providers could be exposed to affected children and families in the future as families start to observe the development of their children. This is due to the fact that some children might have been initially missed, but also that children who were previously exposed to Zika virus during pregnancy may develop symptoms suggestive of congenital Zika syndrome later in life.

B. Family Dynamics and Caretaking

1. Patterns of Power

The analysis revealed that there are mixed perspectives on who is the head of household in dual-parent households. According to one health care provider, fathers are usually the head of the household and provide financial support, but there are also a lot of single-parent and single-mother households. Two care seekers stated that the head of household is determined by the roles and functions that a person has, the ability to provide, and the ability to make decisions, which can be either parent but usually falls to women. Based on this definition, they identified women as the heads of households because they have more control over daily activities. Another care seeker identified that it depends on if the parents are living together; in those situations, the man is normally the head. In one focus group, 7 out of 8 care seekers said both partners are the head of household and 1 of 8 said that it was the woman. The findings reveal that the role of head of household varies by family.

"Different strokes for different folks." (Female care seeker)

"One house, two heads." (Male care seeker)

Participants identified that both parents usually work outside of the home in dual-parent households. Men work in fields such as manual labor, construction, and carpentry, whereas women work as janitors and in

office environments.^a One participant noted that the lines that dictate what jobs men and women do are becoming blurred and that there are no longer gender-specific jobs. Inside of the home, women tend to do the majority of the housework, including cooking and cleaning. In one mixed focus group, half (4 out of 8) participants noted that women do the domestic work, 3 out of 8 mentioned that both shared the work. One participant stated that women do 90% of the work and men do 10%. While the domestic work may not be equally divided, 8 out of 8 participants agree that it should be split 50/50.

Who works or doesn't work does not appear to influence how money is spent and how decisions are made within families. The majority of participants in one focus group said both men and women make decisions regarding money. In separate focus group, 6 out of 8 participants (all female) think that both parents make decisions about money, and 2 out of 8 (both male) think that women make the decisions about money.

2. Caretaking and Child Development

Care seekers identified that both mothers and fathers play a role in caretaking, but 7 out of 10 participants in one focus group identified mothers as the primary caretaker. This sentiment was echoed across all respondent answers, that the mother is the primary caretaker, but both parents are involved in child care. However, this is dependent on who is head of household and if one is a single parent. For single parents, sometimes children live with their father, but more often they live with their mother. Care seekers could not identify a specific law that guides this decision.

When parents care for their children participants noted that women tend to take on more of the role of nurturer.

“Women are nurturers I guess, the men aren't quick to bring that to the forefront, men are more macho-like, a man will take one glance and say 'looks ok', a women will really look, women are nurturers we take control, men are mostly considered the breadwinners and if you try to take that from them it's a struggle.” (Female care seeker)

Fathers participate in activities such as diaper changing, bathing, and later bottle feeding. According to participants, some men don't participate because they don't see it as their responsibility or are scared they may “crush the baby's head”. However, in at least two focus groups, both mothers and fathers expressed that fathers can do just as good of a job as mothers in caretaking.

“A father can actually do all of the things that a mother does.” (Male care seeker)

Table 4 summarized care seekers responses to the question of what makes a good father or mother.

Table 4. Care seeker responses to “what makes a ‘good’ father and a ‘good’ mother?”

Fatherhood (provider)	Motherhood (caretaker/nurturer)
<ul style="list-style-type: none"> ● Be there for their children ● Support children physically, financially, emotionally, spiritually ● Impart their knowledge ● Raise a child even if it's not their biological child ● Be consistent 	<ul style="list-style-type: none"> ● Spend time with her children ● Be nurturing ● Expect that parenting is a full-time job ● Having a beautiful baby ● Willing to make sacrifices and compromises

^a The data collection team noted that the types of jobs participants reported for men and women could be an indication of the populations who utilize and receive health care services at public institutions, i.e. working-class citizens.

While mothers are often seen as full-time caretakers, men are increasingly stepping into their roles as active fathers. This is further evidenced as both mothers and fathers in all focus groups knew steps to assess whether their child is developing properly. Some of these measures include checking the weight, size of the head, growth and eating trends, and following the health facility-provided (development tracker) cards; several parents also mentioned using Google. Men themselves also noted the roles they are playing in childcare.

“I didn’t have a dad growing up so I’m learning as I go along, but I think he (a good father) tries to be there as much as he can, tries to provide, makes sure his child and partner are safe, that’s what I think.” (Male care seeker)

“It’s usually like that (mothers doing the care work), but it’s not supposed to be. If the mommy is there all day, even if we are the ones going off to work and making the bread, she’s still home doing a hard day’s work. You come home and give her an hour or two rest. You have to share the responsibilities when it comes to the child. Some people say mommy has to get up. No sometimes daddy has to get up too. You have to share.” (Male care seeker)

3. Challenges in Caretaking and Disciplinary Practices

The analysis revealed that there are also several challenges to caretaking. Stress among caregivers can stem from lack of finance, problems with spousal or family support, if the child was unplanned, and instances of postpartum depression. Two participants noted that a stress for parents or caretakers can be not knowing what exactly to do; particularly for new parents or parents of children with disabilities. Generally, some parents find assistance using day cares, but getting children into day cares can also be a challenge as many are expensive, some require certain vaccinations, and others may have age limitations on when a child can be enrolled, which sometimes conflicts with parental leave policies.

When the challenge is the behavior of the child itself, disciplinary measures are often utilized. Participants identified that spanking, lashing, shouting, putting children in a naughty corner, and taking away privileges such as TV time and hanging out with friends are the most common forms of discipline used with children. Both mothers and fathers seem to be involved in carrying out disciplinary actions, though fathers many have more weight or may be taken more seriously.

“If they get a little older, and can’t be managed, the father would be called in. Most of the time the father has more power in the home. The children will listen to the father. We have some mothers that are very firm.” (Female care seeker)

While both boys and girls are disciplined there may be differences in the type of discipline used based on the child’s gender. One participant revealed that fathers don’t like to discipline girls and a majority of participants felt that boys were disciplined more than girls. When girls are disciplined there seems to be caution in making sure they are not visibly physically harmed.

“Yes, for me girls and boys are disciplined the same. I think in the community girls are more protected. Stick for the boy and belt for a girl. Don’t want to get marks on her skin. Girls are supposed to be pretty and shouldn’t have marks on their skin.” (Female care seeker)

There is no evidence of disciplinary differences between children with and without disabilities. Both care seekers and health providers revealed that disciplinary practices for children with disabilities can fall to either side of a disciplinary spectrum. Some children are coddled, and the parents are more patient or let the children do what they please. Other parents believe their child is just ‘acting’ or is choosing to behave poorly. These types of parents are stricter and expect their children to sit down, pay attention, and respond in a manner similar to children without developmental challenges. All in all, discipline for children with disabilities is dependent on the parent.

4. Male Participation in Antenatal Care and Well-Baby/Child Visits

The analysis revealed that there is no distinct pattern of male participation in regular antenatal care. Men are generally sparse at ANC and well-baby/child visits, but they are increasingly coming by choice. In the focus group with couples with high-risk pregnancies, 9 out of 9 men had been to ANC visits before and 7 out of 9 go every time. According to the men, they want to go for the visits and it is their choice. However, in both the focus group with couples with non-at-risk pregnancies and the one with parents of children under 5, men and women expressed that male involvement is very much dependent on the man and participation in antenatal care and regular child health visits after the baby is born can vary from man to man. Men across focus groups noted that some men do come all of the time and want to be there with their partners while others mentioned they wanted to be there but were not invited, suggesting a barrier exists either from their partner or the health facility. Participants agreed that the younger generations could have a part to play in this shift.

“... I find that fathers are more accepting to go along and come to the clinics with mothers. Because 10 years ago you probably wouldn’t see that much. You are slowly seeing it now. So, I find the younger youths of today are adapting and paying more attention. It’s a bit more than before because in the past they would never come to the clinic.” (Female care seeker)

Another finding is that pediatric and other referral services appear to receive more men than regular antenatal and well-baby/child visits. For regular ANC and child visits, fathers may come in if mothers have to work but 60-70% of the time a child is brought by their mother, grandmother, or other female relative. Whereas at pediatric and referral service visits, one health provider reported that 60-70% of the time both parents attend and in households where the parents are together the rate is higher. According to the provider, this could be attributed to the fact that once children reach pediatric or referral services an issue may already have been raised and as such there is more of a concern.

Interviews with health providers revealed that they are playing an increasing role in this change and engaging men in a family health model. Providers have reported that they have invited men to participate in ANC and well-baby/child visits and further shared some personal strategies for encouraging men to attend.

“That’s the biggest difference, we don’t just give them [men] a card we call, the opportunity [for child visits] is for both parents.” (Female health provider)

“If acted upon [the suggestion to bring the father], the father of the child can have a better appreciation for the aim of the services we are providing. It would reassure him that it is not a woman’s thing to be involved. I am always encouraging the men to come and congratulate them. It works well having a male share their perspective.” (Male health provider)

“Men are probably just waiting to be asked, they say they are busy, but I generally find that they are happy to be asked, finally somebody is including them in a discussion about their child’s health.” (Female health provider)

Several providers reported that some men who attend ANC and well-baby/child visits are very much engaged and even ask more questions than the mothers. One health provider attributed the increased questions to the fact that dads are not there as often so when they go they ask more involved. Where fathers are unable to make it to ANC and well-child visits both health providers and care seekers noted that they are often involved in other ways such as financing and transport. Overall, provider and care seeker perspectives highlighted that men’s involvement in their partner and children’s health is increasing in Antigua.

5. Health-seeking Behaviors

While men are increasingly involved in their partner and children's health, perceptions of masculinity still exist that keep men away from health facilities even at the risk of their own personal health. Both male

and female focus group and provider participants expressed that men feel they need to be strong because their families depend on them and they cannot be seen as emotional, weak, or unable to provide for the family. This sentiment, noted by both female and male participants, appears to be ingrained in men from a young age. In line with this, male care seekers stated that in general, men tend to trivialize illness and ignore problems and female care seekers identified that men don't come to the health facility because they are afraid of the "white jackets", afraid to face the facts, and don't want to know about their problems. The challenges stem from societal perceptions of what is appropriate for men regarding their health. Female care seekers also noted another social aspect in that men may be busy with work and not prioritize their health.

"They will say you're a boy 'man up'. Some parents will even say 'he's acting'. Sometimes it's the parents, they think boys need to be tough." (Female care seeker)

"Naturally men are stubborn we don't want to always hear the truth, and it can be a lot scary for us because we are taught to be strong and bold, and when we are sick, we are at our weakest point, we are vulnerable." (Male health provider)

"You know men, they always put their work first." (Female care seeker)

When men do seek care for themselves, it is often at a point after they have tried a home remedy, have waited to the point where the pain or issue is unbearable, or they are urged by another family member such as their partner to seek counseling and care.

"With the male it is pride, they will say they tried this home remedy then when they can't do it more then they come." (Female care seeker)

"They say that men don't like to come to the doctor unless they are really really ill. I find that to be true. Or if someone that has an interest in their health. Whatever the problem is, it has become unbearable or bothersome." (Male health provider)

"She will say to go to the doctor, she will make the decision when seeking health for me." (Male care seeker)

Within families, there doesn't seem to be a standard practice when it comes to prioritizing mothers, fathers, boy or girl children in their health care. Several participants stated that in a scenario where the whole family was sick, the children would be the first to be attended to. At least two participants (one male and one female) said that the mother should receive health care first as she is the one who cares for the rest of the family. One male participant said they would triage the situation and send whoever was the sickest first. At least two participants noted that sons would be expected to tough it out and 'man up'. One of the two noted that a boy may simply be wrapped up where a girl would be given consideration and taken to a facility. The opinions demonstrate that to some extent perceptions exist differentiating health needs for boys and girls, and among parents.

6. Parental Leave Policies

According to the Antigua and Barbuda Social Security Board, the national maternity benefit is provided to an insured woman who has given birth to a child and is provided in the form of an allowance, grant, or both (Antigua and Barbuda Social Security Board, undated). A maternity allowance is granted for a maximum of 13 weeks. During this time, the benefit covers 60% of the insured woman's average insurable weekly earnings and she must have worked for at least 26 weeks to gain this benefit. A maternity grant of \$560 is also available to a woman if she or her husband has paid 26 weeks of contributions to social security in the year immediately before the birth of the child. To qualify for the maternity benefit a claimant must: 1) be between 16 and pensionable age; 2) complete an application and submit to the Social Security Office; and 3) after childbirth, complete and submit to the Social Security

Office a signed certification from a health professional stating they had the child. There is no official paternity leave policy for men in Antigua and Barbuda.

The analysis revealed that in reality, parental leave policies may be at the discretion of the employer or office. Women across focus groups mentioned that women are generally granted three months maternity leave but explained that it depends on the job. One woman reported that she received only six weeks. According to focus group participants, to extend their time, some women pair their maternity leave with vacation. Women reported that they are usually able to go back to their jobs after maternity leave.

Men, on the other hand, generally do not receive paternity leave, but this also depends on their job and employer. As focus group participants explained, if a man works for the government, he may receive additional benefits. One female participant mentioned that men receive 3 days. None of the men participating in the focus groups had received any paternity leave. One explanation participants provided was that it could be that if a man is married he may receive days that unmarried men do not. In one focus group 3, men (out of 4) agreed that if you're not married you don't get paternity leave, but if you are married you may get 7 to 10 days depending on the employer. Marital status, participants suggested, may also play a role in antenatal and delivery services. Practices such as these keep men out and uninvolved from early stages. While health providers at the hospital said that 80-90% of deliveries are with a male partner in the room, one client at the health centers reported that unmarried partners are not always welcome in services such as antenatal care.

"They say he is not allowed in the room because we are not married. The doctor has a problem if you are unmarried." (Female care seeker)

The analysis revealed that parental leave policies may pose a challenge to caretaking and further segregate caretaking roles within a household by setting a pattern for decreased involvement of men in child care. After birth, where mothers have time to bond with the children, fathers generally do not. Participants identified that because most children are born out of wedlock, the system does not cater to father's involvement in caretaking and child raising from birth and potentially before that. Furthermore, policies such as these engender familial roles early on particularly within the household and caring for children, perpetuating systems of inequality.

"Our system in the Caribbean doesn't support fathers to play an active role in the child's life- for example, mothers are given maternity leave to help with bonding and I get that but fathers on the other hand, what incentive do they have from the system to be active in the child's life at that point." (Male care seeker)

According to participants, some fathers do choose to take leave but not all fathers, and other fathers are unaware they can take leave (where a company policy may be available) because they are told they have to work, reflecting a need for greater awareness around leave rights. Both male and female participants discussed the need for paternity leave, but at least two health providers discussed potential challenges around paternity leave such as if a man fathers more than one child in a year. If paternity leave were to be offered to unmarried men (or men with extramarital children), would they get it for all of their children? What if they have multiple children in a year? How can employers verify that men are the father and that they will use their leave to care for the child? These are all questions that should be explored before establishing an updated paternity leave policy.

Day care was another option mentioned to support families with their childcaring needs, allowing children to be watched while parents are at work or otherwise occupied. However, challenges still exist, such as conflicts between maternity leave and day care policies. The analysis revealed that day care parameters regarding age requirements of eligible children vary, and some enrollment parameters conflict with maternity leave. Some day cares for example, take children at three months but others don't take children until five months or later. If families choose or only have the option to send their children to day cares for children five months and older, and the mother only has three months maternity leave, this forces the mother to take additional leave, disrupts her normal work schedule, or in some cases results in a mother

3. Other Impacts of Disabilities

In addition to the impacts on families, participants expressed feeling that PWDs may experience more violence, bullying, and teasing. Multiple participants stated that girls may be especially prone to violence. Participants expressed that this violence could come from friends, siblings, classmates, parents, or strangers. One health provider shared that when PWD are not be able to express themselves, they can get angry or violent, which may elicit violence from parents, family, or friends. Several health care providers also expressed concerns around neglect, stating that parents may leave their children with disabilities at home or locked in a room alone.

“The weaker the female in the community appears to be, the perception is that it is easier or not as challenging to manipulate or have my way with her.” (Male health provider)

4. Services for Children with Disabilities

As mentioned throughout the previous sections, services, such as specialized health care and education, for PWD exist. However, all participants agreed that more needs to be done to improve these services and to increase access and awareness. One focus group participant explained that the Adele School for Special Children was established for students with disabilities and special needs but that some children with special needs still attend the regular public schools. She expressed concern over this considering that there are no special education instructors at the public schools, and she also recognized that the Adele School was not equipped to handle such a range of disabilities and special needs. Participants and health providers (outside of the parents of PWD group) were able to identify several other services including the Hope Project, the Alliance Club, and the Care Project. They also expressed that Antigua needs improved PWD-friendly public infrastructure such as disability-friendly public bathrooms, transportation, and access to public spaces. All the KIs who were health providers noted that their facilities are equipped with basic support for PWD including ramps and some rails.

Parents of children with disabilities expressed that there is a lack of awareness of services available to them and their children at the primary health center and more broadly in Antigua. Many did not know of the Care Project until their child was a few years old – they expressed a sincere gratitude for the Care Project but wished that they had known about it sooner considering that regular day cares would not accept their children. These parents, the staff of the Care Project, and other health providers felt that the Care Project needed to be expanded to accommodate more people. Parents of children with disabilities expressed a desire for more awareness about the specialists (e.g., speech therapists and physical therapists) on the island, their hours, and the associated costs. Finally, the parents felt that there are not enough psychosocial support services available to them. They expressed a desire for a support group for families of PWD and exchanged contact information at the end of the focus group in hopes of starting one in the future.

“We need more group support, like AA meetings, but for kids like that or for mothers.” (Parent of a PWD)

“They used to have a program every Tuesday for families of PWD. Someone from the community would come, but I haven’t seen the lady for a while. She would assist them on a one-on-one. I haven’t seen her for a while.” (Female health provider)

D. Additional Takeaways

1. Socio-cultural Shifts

There are generational, cultural, social shifts – and perceptions of shifts – happening in the country that are affecting connectedness of persons across the island. This connectedness is in the form of shared experience and responsibility or support. One connection that was brought up during multiple focus group discussions was the connection with neighbors. Participants felt that this relationship was much stronger

in previous generations than it is now. One participant explained that their parents talked to their neighbors, but this generation does not because people want their own privacy, or they don't like their neighbors. Several participants noted that this reflects a shift in personalities across generations.

Many care seekers and providers discussed that their parents may have had other support systems. While grandparents, older siblings, or other female relatives (more immediate family) were mentioned as some of sources for additional childcare support, the analysis revealed a reduced role of the community (extended family members, neighbors, friends, organizations) in childcare. While a few participants embraced the role of the larger community, the majority noted this is no longer a common practice.

"In my opinion, I believe the whole community should take care of that child. The mother or the grandmother or whoever elder sibling in the house." (Male health provider)

"Some do, some don't (have support). It depends on the parents. When I was going up the whole village would raise me. But now if mommy says don't talk to neighbor Tommy and Jane, you don't talk to Tommy and Jane." (Female health provider)

"A lot has happened to us as a people. It has caused great division among ourselves." (Male health provider)

Dr. Sharla Blank in her paper, "An Historical and Contemporary Overview of Gendered Caribbean Relations," found that when looking at relationships dynamics, Afro-Caribbean populations experience low rates of legal marriage and high rates of single-motherhood (Blank 2013). Specifically, in the Eastern Caribbean she noted, almost 70% of children are born into non-nuclear families. Additionally, a Bernard van Leer Foundation paper by Barrow and Ince found that (Barrow and Ince 2008):

"Many of the people we met said that Caribbean communities are less supportive than in the past. This means that children are cared for increasingly by their mothers. Despite stereotypes of extended Caribbean families, many mothers are not involved in a wide network of female support. The feeling is that families are drawing in on themselves because of cultural change, including more television watching, and the fear of crime, especially from gangs of drug-fueled young men."

Similarly, the gender analysis revealed that there has been a generational shift and a lessening importance of the extended family and a growing importance of the nuclear or immediate (in the case of single parents) family. However, participants also noted that there is less of an interest in marriage now and that many children are born out of wedlock and into single-parent households. According to the latest 2011 Antigua and Barbuda Population and Housing Census, only 27% of the population is legally married (Government of Antigua and Barbuda 2014). Interestingly, there were nine soon-to-be-fathers at the focus group of high-risk pregnancies. All of these men reported attending ANC visits and planned to be there for the birth, but none of the couples were married.

"Kids are having kids and now things are all different." (Female care seeker)

"It's all different now. The younger generation it's different; used to be raised with whole family. Now it's more about the nuclear family over the extended family. Family dynamics have changed." (Female care seeker)

"People are not interested in marriage now, before more people got married. They are scared, don't want to, or may have had a bad experience. People don't face stigma being or not being married or having children outside of marriage" (Female care seeker)

This shift in connectedness has implications for the role of the health center. The MOH must be cognizant of these factors and their growing role as they develop new policies and programs.

"As the role of the community is decreasing or changing, the role of the health center is increasing." (Male health provider)

Migration in and out of Antigua has also affected cultural dynamics on the island. Rates of immigration are high – 13 of 57 participants (22 percent) in the gender analysis were not from Antigua. These participants primarily came from the Dominican Republic, Haiti, Dominica, Guyana, and St. Vincent. Immigrants to Antigua face additional challenges in seeking health care. Participants noted that there are financial barriers due to challenges accessing medical benefits cards and language barriers at clinics and the hospital.

2. Violence

Child abuse and violence against women exist in Antigua – all health providers interviewed for the assessment stated that they have seen a case of violence in their work. While some tools and policies exist for prevention and response, they need to be updated and rolled out at the health facility level. For example, according to one health provider, policies on handling cases of domestic violence and child abuse were developed in the 2000's, but nurses and community health aides did not express knowledge of these policies. Rather, they explained that if they suspected abuse, they would refer the client to their supervisor. They stated that they were unaware of a protocol or official referral system, but they knew to tell women to go to the police or to organizations such as Women Against Rape. A few health providers identified a clear chain of command for reporting abuse but agreed that there is a need to increase understanding of policies and processes through continuous training. One health provider who was instrumental in developing the previous policies acknowledged that they are in need of an update and a clear roll-out strategy.

3. Condom Use and Family Planning

When asked about contraception, most focus group respondents expressed that they and their peers primarily use male condoms and that women have negotiating power over whether condoms are used during sex. In one focus group, all participants stated that it is the woman's choice whether a condom is used. When probed regarding males' reactions or what happens in situations of a man's refusal, the female participants noted that some women may submit but most would then refuse sex.

"No condom no sex." (Female care seeker)

"No condom? Lock down shop." (Female care seeker)

However, there are myths around condoms' effectiveness. One focus group spoke at length about "counterfeit condoms" that give people an infection or disease when they use them. The brand that they referenced is the same brand given out by the clinic. When probed about the danger of this myth, participants agreed that it could potentially lead to a reduction in condom use. Furthermore, according to participants across the different focus groups, the majority of pregnancies in Antigua are not planned. Therefore, there is a disconnect between the perceived high usage of condoms by health professionals and the actual usage. Additionally, several participants expressed that condoms are ineffective. Others think that "passion" and "urgency" sometimes get in the way of condom use. Finally, several participants expressed that once women start using other contraceptives such as the pill or injections (the two most frequently mentioned methods after condoms), they stop using condoms. This has serious implications for sexual transmission of many infections, including the transmission of viruses such as Zika.

"Once they have contraception, they don't remember what a condom is." (Female care seeker)

4. Psychosocial/Emotional Services

According to participants, more psychosocial care, counselling, and therapy is needed at all levels. Participants expressed a desire for more psychosocial care at the clinics and the hospital. They agreed that this could range from social workers to group support opportunities. Currently, there is only one certified social worker at the hospital and her work load is incredibly heavy. While more social workers would be beneficial, participants felt that support groups could be equally effective.

Like the parents of PWD, the men and women with high-risk pregnancies expressed a desire for a “mental health support group” where they could discuss services, challenges, advice, and generally support each other emotionally. However, one care seeker in the non-at-risk antenatal group noted that if additional support services were available, parents might not use them given the small size of the island and the affinity for people to know intimate details about each other. Therefore, there should be measures put in place to ensure confidentiality and establish group norms around privacy.

“Being realistic we live in a small island, everyone knows everyone’s business. So, it would be best to go to your sister, a best friend you trust more, then go to a counseling class. Because that person that goes to the counseling class could tell your business. I would advise everyone have a best friend.”
(Male care seeker)

Finally, one health provider noted that while there are trainings for the staff on empathy and cultural diversity, there could be significantly more training on how to integrate therapeutic and counselling approaches into all health providers’ daily work.

5. Other Barriers to Quality and Equitable Care

Across all KIIs and FGDs, participants noted challenges with accessing quality and equitable care. These challenges ranged from financial barriers blocking access to care, to the quality of care they received at health centers and hospitals. In terms of financial challenges, participants understood that community health centers are free and provide services for everyone (there used to be a policy that one could only receive care at their local clinic, but that policy has shifted to allow for greater access to care). However, they identified financial constraints in seeking specialized care or services at the hospital and other referral facilities. Participants noted that unemployed migrants do not have access to a medical benefits card. Even for those with medical benefits cards, participants explained that the plan does not cover all health care costs. One care seeker noted that she was paid back only 30% of the associated costs for a major medical procedure.

“Health care is accessible but not affordable. The clinics are for free, the expensive part is when you go to the doctors and you have to spend money, and it is beyond your paycheck, so I think the government needs to do something about it.” (Female care seeker)

Focus group participants expressed that customer service and bedside manners at facilities need to be improved. One care seeker said that her concerns are not taken seriously, and another noted that she has been talked down to by nurses and health providers. Multiple care seekers stated that health providers are too “lackadaisical”, “rude”, and lacking “personal consideration”.

“When you seek medical attention you are already stressed, certain things might trigger you and our health care providers need to be aware of that and understanding.” (Female care seeker)

One focus group identified the root challenge as a lack of accountability within the health system. They claimed that there is no way to provide feedback or to report bad service and that there is no disciplinary action against poor performers. However, staff at the hospital noted that there is a quality department that is supposed to monitor customer feedback including reports of bad service. According to the hospital’s website, any concerns should be reported to “the person in charge or the manager of the department” (Mount St. John’s Medical Centre, undated). The feedback from the focus group participants however, highlights the need for greater awareness around options for (provider and facility) feedback and approaches to accountability at the hospital and clinics. One health provider did not agree with care seekers that there is such a problem with quality of care – he expressed that most of his colleagues have good customer service and there may be only a few people who aren’t well-versed in customer care. While health providers and care seekers alike recommended trainings for providers in customer service and bedside manners, two health providers explained that there are deeper institutional issues. One noted an overall challenge with staffing and systems, stating that the health centers and hospitals are understaffed, the staff are underpaid, and they are lacking key technologies and materials. This rush (due

to understaffing) and frustration is, according to her, impacts client care. Another health provider attributed the challenges to morale. She believes that health providers do not feel valued and do not see the impact of their work. They feel underappreciated which diminishes their motivation and their compassion. She expressed that increasing staff morale would go a long way in improving the quality of care provided to clients.

Participants identified several other challenges including that medication is not always available at the community health center, the clinic hours conflict with work schedules, community health centers can be very crowded, parking for expectant mothers and PWD is inadequate at the hospital, and some specialists do not exist in Antigua, so you have to travel overseas to receive certain procedures. One health provider discussed the additional barriers for homosexual persons.

“One law they are trying to change is the law against homosexuality. It is illegal, it is practiced, but because there is an actual law, persons that may have this sexual preference may feel embarrassed to access public health services. Instead, they may choose to go to a private clinic, but they may not be able to support themselves financially, maybe not in a continuous manner. There [may not any privacy or confidentiality] in the public health services which can lead to stigma. Not that I’ve seen anyone go to prison, but culturally they are stigmatized.” (Female health provider)

The focus group of high-risk pregnancies identified additional concerns around the safety of deliveries at the hospital, the lack of concern (on the part of nurses) regarding warning signs throughout their pregnancies, and an insufficient number of chairs for expectant mothers at the hospital.

“When you are sitting down dying and have to wait 4 hours, it’s an experience that we don’t want.... It was very traumatizing for me.” (Female care seeker)

“If they don’t make the delivery safe, we will not want to have more babies.” (Female care seeker)

VI. RECOMMENDATIONS AND WAY FORWARD

Although Zika is no longer a significant threat to the Caribbean region, lessons from the Zika outbreak and findings from this analysis can be applied to the health system more broadly. Several gaps and opportunities for strengthening health services and delivery were identified throughout the analysis. Addressing these barriers, filling these gaps, and seizing identified opportunities will be essential to prepare the health system to handle any future disease outbreaks and to continually provide quality care for the people of Antigua and Barbuda. The health system also has the opportunity to promote gender mainstreaming and to use a human rights-based framework which will result in more equitable and quality services. The recommendations provided in this report are inclusive of those provided by KII and FGD participants and also recommendations that the research team deemed important to fill the identified gaps and challenges.

The social inclusion of PWD, including children and families affected by Zika, needs to be urgently addressed. The Government of Antigua and Barbuda, including the Ministry of Health, has opportunities to improve services and support systems for families and strengthen provider capabilities – several recommendations for doing so are outlined below. However, in using this approach, policy makers and implementers must also be aware of generalizations about “disability” or “people with disabilities” that can be misleading. Like their peers without disabilities, PWDs have diverse gender, age, socioeconomic, sexuality, ethnic, and cultural identities (WHO 2011; aecid, WEDecide, UNFPA 2018). Disabilities themselves and the associated needs also vary widely. These perspectives must be taken into account as response efforts work to improve equitable quality health care for families.

Recommendation 1: Improve Public Education and Awareness

Participants felt that there was limited public understanding and awareness in several key areas that could be improved with public education, information sharing, and awareness-raising campaigns. The data collection team recommends that the MOH explore opportunities for improving public knowledge in four critical areas.

Improve public understanding related to disabilities: families of PWD expressed that there was a need for improved public understanding related to disabilities to ensure that stigma and discrimination were reduced. This could be addressed through public education, such as MOH-sponsored PSAs on TV or radio or posters in health centers. This is consistent with findings from the literature showing that across the region, there is a need for on-going public education and awareness programs to address issues of abuse, stigma, discrimination, marginalization, and exclusion of PWD (UNICEF 2013).

Greater information sharing around services available to families of persons with disabilities: the focus group with families of PWD identified a need for greater information sharing around services available for PWD or families of PWD, including health services, education opportunities, and financial support. In addition to social workers knowing this information, the MOH should ensure that health care providers know how to properly refer patients with disabilities. Similarly, a partnership with the education sector could help parents receive this information when their children first start attending school.

Increase awareness of available services at health centers: across all FGDs, there was a lack of awareness around what services were available at various health centers and people wanted to know more. A doctor at Mount St. John's suggested that improved public health campaigns and a heightened awareness of what illnesses could be prevented, treated at home, or at a community health center could also help reduce the high burden of clients on the hospital. Another health provider agreed that education (or training) for families on well-baby care or preventive care specifically, could be beneficial.

"I think that there can be more training for families. I'm thinking that if it's a situation that the baby is not sick, it doesn't rest on the health provider to keep the baby well, it rests on the family. So, more needs to be done for the families [to] maintain healthy babies so they can be healthy adults." (Male health provider)

Strengthen public education on family planning topics: there was an identified gap in knowledge regarding the efficacy of contraceptives, family planning options, and the benefits of condoms. Therefore, improved public education on these topics may reduce the number of unplanned pregnancies and could mitigate sexually transmitted infections including any potential future resurgence and spread of Zika virus.

Public education and awareness related to stigma and disabilities, available services (health services, financial support, social security), public health, and family planning would be instrumental in improving the health of Antiguans and reducing unwanted discrimination. This awareness raising could be done through jingles, advertisements on television or the radio, posters in health centers and hospitals, community-based campaigns, and through programming at schools.

Recommendation 2: Engage men across the spectrum of antenatal, neonatal, family, and personal health services

The findings revealed several pieces of key information with regards to men's health seeking behavior. First, men are involved and are increasingly present in referral and high-risk pregnancy situations. Second, men are increasingly coming to regular (non-risk) ANC and well-baby-child care with their partners and children, but not as much as they do during high-risk pregnancies or for referral visits. Health providers noted that not many men attend regular visits with their partners, but the numbers are starting to increase. Third, the analysis revealed that while men are coming to the health facilities with partners and children, they are not utilizing the health system for their own health and well-being. With this learning there is an opportunity to maintain men's involvement in referral and high-risk scenarios, increase their involvement in regular ANC and child visits, and improve their own health seeking behavior.

Providers should increase efforts to encourage men to visit health centers and hospitals. There should be posters at health centers and hospitals outlining that male partners are welcome at ANC visits, during delivery and during well-baby clinics; these posters can also outline the benefits of this male involvement. Providers should also encourage women to bring their male partners for these visits. Additionally, some providers have been successful in calling men personally, and these strategies have been influential in making men feel welcome and secure in their family's health. In addition to encouraging male engagement in maternal and neonatal health, providers should apply this strategy to men's individual care and engage men in their personal health during referral, high-risk, and regular well-child visits. Furthermore, the MOH should explore opportunities for raising public awareness about and address the harmful concepts of masculinity that negatively impact men's health seeking behavior.

Recommendation 3: Increase counselling opportunities and psychosocial support and establish community support mechanisms

As outlined above, participants expressed a desire for more counselling opportunities and community support mechanisms for (but not limited to) families of PWD, victims of violence, first-time mothers and parents, and single parents. Counselling should be provided at the hospital, health centers, and in schools and linked with mental health programs where possible. Counselling and support should be both formal, through social workers, and informal through MOH or program sponsored support groups. The group of high-risk pregnancies recommended classes for expecting parents where they could learn about birthing and parenting; they could then understand that others are going through similar challenges and they could work through them together.

"I don't know if they do classes or have groups for first time parents, but they should try to prep you for when you go up to the hospital." (Male care seeker)

"When I go through the different changes, I want someone there. I want parenting sessions." (Female care seeker)

"We have groups every once and a while—but workload is too heavy. We used to have a group for women who lost babies. It would be super helpful to do things like that again, but we just don't have time. But we should. It makes a huge impact." (Female health provider)

Outside of these special cases, participants expressed a desire for more counselling and psychosocial support for all clients. For counselling to be provided in health centers, there must be training for providers on psychosocial support and counselling approaches. Options for these trainings are outlined under **Recommendation 5**. With training, health providers could provide a certain level of support for all of their clients, but pairing this with more staff social workers at health centers would be ideal. It will be essential, with an additional focus on counselling, to ensure client confidentiality. Antigua and Barbuda are small islands and multiple participants expressed concerns over counselling for fear of their personal information being shared. Therefore, in addition to training on counselling approaches, clear policies and training on confidentiality will be essential.

To continually improve the knowledge of these social workers and the level/quality of care provided to clients, one health provider recommended establishing a 'network of psychosocial care providers' across the Caribbean islands. As there is a limited number of professionals in this space in Antigua and Barbuda, fostering communication across the Caribbean islands would allow for knowledge exchange of best practices, new research, and solutions to common challenges. This network could be over Facebook or WhatsApp and could be established and supported by ASSIST and WI-HER, which has connections with psychosocial support professionals in the Caribbean nations. Finally, several participants recommended providing scholarships for students to study counselling, social work, speech therapy, physical therapy, etc. (key areas that currently face staffing limitations) to increase the number of qualified professionals for these critical services.

Recommendation 4: Improve coordination with other ministries/departments for public health outreach and social support

Several of the challenges outlined above are not under the domain of the health system. However, coordinating with other ministries and sharing best practices and approaches could result in an overall more supportive environment for PWD, families, and an overall healthier population. First, the MOH should coordinate with the ministry in charge of infrastructure and public works to ensure that new buildings are disability-friendly. Buildings should be wheelchair accessible with ramps and larger bathroom stalls, and sidewalks should include inclines to allow persons to reach them safely. Furthermore, public transportation should be improved to further accommodate PWD. This includes ensuring that the wheelchair accessible bus to the hospital runs frequently and on time. These recommendations are consistent with the literature that shows more needs to be done to enable persons with disabilities to maximize their potential to actively participate in society (UNICEF 2013).

“The community is not built for persons with disabilities. No one is looking out for them in public spaces. Should at least be the case in the capital. For example, every new building that goes up should have these changes, they should be mandatory for public spaces. A lot of new construction going up, so there is a unique opportunity to standardize things properly.” (Female health provider)

Second, the MOH should continue coordinating with the education system to integrate sexual education and other health programming into schools. Considering the high rate of adolescent pregnancies, better health and sexual education could be instrumental in helping young men and women understand their options, plan their pregnancies, and have the added benefit of helping to reduce sexually transmitted infections. According to World Bank data, the adolescent fertility rate (births per 1,000 women ages 15-19) is 44.7% in Antigua and Barbuda (The World Bank, undated).

Recommendation 5: Create a web-based training platform for providers and facility staff

Across all FGDs and KIIs, participants recommended training for staff. Training topics included gender awareness and sensitization, continuing medical education, sensitivity and cultural diversity training, working with PWD, customer care/respectful care, client confidentiality, and handling child and gender-based violence and abuse. Conducting many trainings can be timely and costly and also difficult to reach every provider every time, which is why the analysis team recommends establishing a web-based training platform for providers and facility staff. One health provider suggested a similar approach, explaining that it would make training more accessible and therefore less burdensome. This platform, which could mirror ones such as PAHO's, could have a range of training opportunities. Some of these could be mandatory, where providers have to fulfill yearly mandatory credits to keep their licensure. Re-taking trainings ensures that essential information is not forgotten and allows the space for updates to best practices or new medical findings. Other trainings could be voluntary to allow for professional development and some could be live in the form of a webinar by ASSIST or WI-HER staff. Trainings should also be available for health facility staff who are not in provider functions such as the front desk, records management, and volunteers who may also have contact with clients. The first impressions and client experience can also influence future health-seeking behaviors of clients.

Recommendation 6: Update outdated tools and policies based on input from community members and providers and make them more accessible

Throughout the findings presented above, several gaps in tools and policies were outlined. These include, but are not limited to, maternity and paternity leave policies, a gender-based violence referral policy, and a child abuse referral policy. More research is needed regarding maternity and paternity leave options and best practices based on the experiences of similar cultures and communities. For the violence referral policies, the MOH should work with experts in these fields including WI-HER and WAR to ensure that policies and practices are based on best practice while also being locally relevant. Once updated policies are in place, the MOH should ensure that they are available in other languages (Spanish and

French/Creole) and that providers are trained on them. There must also be a way to track implementation and impact of these policies using clear and easy to measure indicators such as a checklist for tools and a survey for both providers and clients.

Recommendation 7: Improve referral systems

Participants – providers and clients – recommended that referral systems be improved through better coordination across the health system. There is especially a need for more linkages between public health facilities and private health facilities which clients may be referred to for specialized care. To improve these referral pathways and links between public and private health facilities, the MOH should look at existing policies and practices to ensure that they are clear for all providers. Participants also expressed a desire to ensure that clients understand their financial support options. Therefore, when health providers and social workers refer patients, they should provide as much information as possible about the need for additional care, the availability of the services referred, the service locations, and the cost to allow the client to make an informed decision regarding their care.

Recommendation 8: Strengthen supporting mechanisms to continuously improve the quality of care

Multiple challenges with the quality of care in Antigua were outlined above. These included insufficient human resources, low pay, low motivation and morale, poor customer care and lack of empathy. The analysis team recommends that the MOH look at staffing levels to determine if they are sufficient and if pay is adequate to motivate staff and attract high quality applicants. One doctor also recommended improving recruitment strategies for young professionals to heighten their interest in medical or public health professions.

Once staff are on board, they should be adequately trained in respectful care and customer service. This was outlined in **Recommendation 3**. Hospitals and health centers should continue to motivate staff to boost morale. One health provider suggested motivational posters in places where staff would see them and having staff appreciation lunches or events. Certificates or awards are additional options for motivation, increasing friendly workplace competition, rewarding positive performance, and empowering individuals.

Feedback and accountability towards clients are also key. Positive feedback will further motivate staff and demonstrate to health providers the value of their work and the impact of quality care on a patient. Feedback on how to improve client-centered care will provide clients an opportunity to voice their needs and preferences and will also give health facilities an opportunity to address them in an effective way. The quality department at the hospital can serve as a mechanism for a feedback loop between clients and health care providers – clients will be able to provide feedback on their care and the quality department can inform clients on how their feedback has been received, where it is in the process, and any action taken. The quality department should ensure that this feedback is used to continuously improve quality of care and reward good patient-centered practices.

These recommendations should not be approached alone. The analysis team recognizes that the health system is complex and one training or a new staff member will not alone result in improvements to the quality of care and ultimately to health outcomes. Rather, small changes can be made across the system to shift the mentality of providers, update their approaches, inform them of new policies, provide them with the time and space to provide the optimal care, improve public health education and awareness, and to engage men and women in health services. One provider summarized this sentiment:

“Staff have good foundation and basic training, they are smart and capable but they need that continuous education. Yet when we do receive some training, if it is not utilized or encouraged overtime it goes. Or if your supervisor pushes you to see clients in 15 minutes then you cannot provide the care you might want and the training will never be used. We need to think of not just education but how clinics are structured so there is equity and quality.” (Female health provider)

Recommendation 9: Establish a one-stop comprehensive center at the community level

Throughout the analysis, participants expressed a desire for more easily accessible services. This includes locating specialists together in one center or complex and offering night and weekend hours. This is especially important for families—particularly families of persons with disabilities—who may face additional challenges securing transportation. One provider described the ideal situation as one that would create a referral unit that could provide all the services such as education, counselling for well-visits, counselling for sick-visits, social work, financial assistance, and nursing. Currently these services are spread out for referrals, and respondents reported that they are sometimes unable to reach the services they need. While the feasibility of such one-stop comprehensive care center is unclear, organizing these services as close as possible would improve geographic access to these services and help individuals and families who currently have to find transport and use resources (financial, time) to reach many separate locations.

VII. CONCLUSION

This gender analysis identified key gender-related barriers and gaps that influence newborn health services and well-baby care systems with a focus on babies and families affected by Zika and other similar conditions, causing neurodevelopmental disabilities. Through FGDs and KIs of 70 participants, this analysis identified challenges, best practices, approaches, and opportunities related to family dynamics and well-baby care in the context of Zika in Antigua. Using these findings, the data collection team presented nine recommendations to improve family health care, services for persons with disabilities, and generally the health system in Antigua. These recommendations were developed to guide the MOH in preparing the health system to manage future disease outbreaks and to continually provide quality care for the people of Antigua and Barbuda.

REFERENCES

- aeacid, WEDecide, UNFPA. (2018). Young persons with disabilities: Global study on ending gender-based violence, and realising sexual and reproductive health and rights. https://www.unfpa.org/sites/default/files/pub-pdf/Final_Global_Study_English_3_Oct.pdf.
- Antigua and Barbuda Social Security Board. Maternity Benefits. <https://www.socialsecurity.gov.ag/benefits/maternity-benefits>.
- Barrow C, Ince M. (2008). Early childhood in the Caribbean. Bernard van Leer Foundation. <https://files.eric.ed.gov/fulltext/ED522741.pdf>.
- Blank, S. (2013). An historical and contemporary overview of gendered Caribbean relations. *Journal of Arts and Humanities*, 2(4), 1-10. <https://theartsjournal.org/index.php/site/article/view/90/89>.
- CARPHA. (2018). Advocacy from CARPHA and CARICOM Results in Zika Label being Removed from the Caribbean. <https://assets.bwbx.io/documents/users/iqjWHBFdfxIU/rpTsKyF9xehw/v0>.
- Centers for Disease Control and Prevention (CDC) (2018). Zika virus: Transmission methods. <https://www.cdc.gov/zika/prevention/transmission-methods.html>.
- CDC (2019). Data & Statistics on Zika and Pregnancy. <https://www.cdc.gov/pregnancy/zika/data/index.html>.
- Government of Antigua and Barbuda. (2014). Antigua and Barbuda 2011 Population and Housing Census. <http://caribbean.cepal.org/content/2011-population-and-housing-census-antigua-and-barbuda>.
- Huang, Pien. (2019). Zika: Researchers Are Learning More About The Long-Term Consequences For Children. NPR. https://www.npr.org/sections/goatsandsoda/2019/10/09/768629177/zika-researchers-are-learning-more-about-the-long-term-consequences-for-children?utm_source=npr_newsletter&utm_medium=email&utm_content=20191010&utm_campaign=goats-and-soda&utm_id=34768467&orgid=.
- Mickle M, Faramand TH, Dale K. (2019). Eastern and Southern Caribbean – Antigua and Barbuda, Dominica, St. Kitts and Nevis, St. Vincent and the Grenadines: Gender Considerations in the Context of Zika Emergency Response Programming. *Desk Review*. Chevy Chase, MD: University Research Co., LLC (URC).
- Mount St. John’s Medical Centre. Webpage. <http://www.msjmc.org/rconcerns.html>.
- PAHO/WHO. (2017). Zika Epidemiological Report: Peru. 25 September 2017. <https://www.paho.org/hq/dmdocuments/2017/2017-phe-zika-situation-report-atg.pdf>
- PAHO/WHO. (2018a). Zika cases and congenital syndrome associated with Zika virus reported by countries and territories in the Americas, 2015 – 2018 Cumulative cases. https://www.paho.org/hq/index.php?option=com_docman&view=download&category_slug=cumulative-cases-pdf-8865&alias=43296-zika-cumulative-cases-4-january-2018-296&Itemid=270&lang=en.
- PAHO/WHO. (2018b). Characterizing Zika Circulation in the Post-epidemic Period. https://www.paho.org/hq/index.php?option=com_content&view=article&id=14752:characterizing-zika-circulation-in-the-post-epidemic-period&Itemid=41716&lang=en.
- UNICEF. (2013). State of the world’s children: Eastern Caribbean area supplement: A stakeholder’s survey: Their opinions on the issues and challenges facing children with disabilities.
- WI-HER, LLC. iDARE Approach. <http://www.wi-her.org/areas-of-expertise/idare-approach/>.
- World Bank. (undated). World development indicators. <http://databank.worldbank.org/data/reports.aspx?source=world-development-indicators>.
- World Health Organization; The World Bank. (2011). World report on disability.

APPENDICES

Appendix 1: Focus Group Discussion Guide



FOCUS GROUP DISCUSSION GUIDE Prepared by WI-HER, LLC

Location: _____ Date: _____

Group Type: _____

Introduction:

Present objectives and estimated time, present the rules of participating in the Focus Group Discussion, read and ask participants to sign the consent form if they agree with what is planned and want to stay, and thank them for their time and the information they provide.

Objective:

Check Zika awareness and knowledge. Identify key gender-related barriers and gaps that influence newborn and well-baby care. Gather opinions on childcare practices. Collect perspectives on children with disabilities. Evaluate familial, communal, and health facility support services.

Zika Awareness and Knowledge

1. Have you heard of Zika virus? What have you heard? How is Zika transmitted? What are consequences of Zika virus during pregnancy?

Family Economics and Decision-Making

2. Who in your family works outside of the home? What type of work do they do? Who in your family works inside of the home? What type of work do they do? Who is considered the head-of-household in your family?
3. If a family member is sick, who decides when they go to their health center? Where does the money come from to pay for any health services? Do women, men, girls, and boys in your family have the same access to money for health needs?

Well-Baby Care and Long-Term Caretaking

4. In your opinion, who is responsible for baby care after a child is born? (Mother, father, extended family, neighbor, other member in the community?) Does the role of caretaker fall primarily on one person? Who? Does the primary caretaker have family or community support to help them with childrearing? Do fathers interact with their babies or children?
5. How does the care of children with congenital zika syndrome or other disabilities affect the caretaker? Which are the main changes in the life of this caretaker (loss of job, school abandonment)?
6. Do fathers ever accompany their partners to antenatal care visits, to the birth, or well-baby care visits?
7. How would a woman react if a health provider suggested bringing her partner to baby check-ups? How might a man react if his partner suggested he attend baby check-ups? What are some principle

reasons a man may not want to attend baby check-ups? Would a man's opinion or attitude on attending baby check-ups change if the suggestion came directly from a health provider, family member, or friend?

8. Do you know how to assess if a child is developing correctly for their age group?
9. In your opinion, what are the primary stressors a primary caretaker faces?
10. Who takes care of children until they start pre or primary school? Do they have any support from other people or institutions? Where do they stay? (At their primary home, at a family member's home, at a neighbor's house, at a friend's house, in a daycare, other? Why do they stay there? Who is usually taking care of the children at this location?)
11. If children misbehave, how are they disciplined? Who is responsible for providing disciplinary action within a family? In your experience or in general, do you think children with disabilities are disciplined? The same or different as children without disabilities?
12. *(If time permits: In your opinion, what are the biggest health risks to children under the age of 5 in your community?)*

Impacts of Disability

13. In your opinion, how might a parent feel who has a child with disabilities? How are people viewed who have children with disabilities (by their family, friends, neighbors)? (Do they feel blamed or stigmatized?)
14. How are family members affected by Zika and /or disabilities viewed by individuals in their community when they seek counseling or other support services? How are they viewed by health professionals?
15. How are children with disabilities treated in your community? In general, are girls and boys with disabilities treated the same in their homes, by their families, friends, and community?
16. In your opinion, are persons with disabilities in your community stigmatized, discriminated against, marginalized, or excluded in society? How are they? Who commits these acts?
17. In your opinion, are children or persons with disabilities at risk of violence in your community? What types of violence? Are boys or girls with disabilities more vulnerable to violence? Are parents who have children with disabilities vulnerable to violence?
18. Do children with disabilities have access to health services? Is cost of care (medical/specialist visits, transportation, medicine etc.) a barrier to accessing care? Based on your general knowledge, what support services are available at health centers near you for families with children with disabilities (psychosocial, support groups, referrals for community organizations, etc.)? In your opinion, do individuals and families take advantage of these services?
19. Do boys and girls with disabilities get the same care? In your opinion, do they receive equal health care or assistive devices from health facilities and professionals?
20. Do children with disabilities go to school? Where do they go to school? Do community schools have specialists, infrastructure, or other support elements for children with disabilities?
21. What services do you know of that can help individuals with disabilities and their families? In your opinion, what needs to be done to help persons with disabilities actively participate in society?

Appendix 2: Key Informant Interview Guide



Guide for Key Informant Interviews Prepared by WI-HER, LLC

Location: _____ Date: _____

Service: _____

Name: _____ Sex: _____

Job Function: _____

Introduction:

Present objectives and estimated time, and thank them for their time and the information they provide.

Objective:

The objective of the Key Informant Interviews (KIIs) are to gain first-hand insight into how health professionals understand the Zika epidemic and impact in their country and to identify gender-based biases, constraints, and other influences to quality of health care and support services.

Zika Awareness and Knowledge

22. Have you heard of Zika virus? What have you heard?
23. In your work, have you ever come across cases of Zika infection? Were any of these pregnant women? Have you provided health services to any woman, man, couples, or families with children affected by Zika-related birth defects, microcephaly, or congenital Zika syndrome? What services did you provide? What services were you unable to provide?

Family Economics and Decision-Making

24. In your opinion, who is usually responsible for bringing a sick family member to a health facility in your community? Who is responsible for providing any financing related to paying for those health services? Are women, men, girls, and boys afforded the same access health needs by their families? What difficulties do families face to receive proper specialist and therapies for their sick children? (If time permits: Do you know of any laws or policies that may benefit or hinder girls, boys, women, or men in accessing the health care they need?)

Well-Baby Care and Long-Term Caretaking

25. In your opinion, who is responsible for the care of a child with CSaZ or other disabilities?
26. Do men ever accompany their partners to antenatal care, the birth, or well-baby visits? Or does anyone else accompany the mother (grandmother, mother, sister, other family, friends etc.)?
27. When children are born with CSaZ or other disabilities, what are the main challenges faced by the family and the mother (abandonment, marginalization, etc.)?

28. Has a man ever brought in his child to a health consultation without a female partner or family member? How is he treated in the health facility? In your opinion, what or who influences men's attitudes on seeking individual or family health services?
29. Have you ever suggested to a woman to bring someone with her to antenatal consultations or well-baby care consultations? Who do you suggest? How do women usually react when you make this suggestion? In your opinion, how do you think a man would react if his partner asked him to accompany her to the child's health consultation?
30. From your perspective, who is responsible for taking care of children in the home? Mother, father, extended family, neighbor, other member in the community? Does the role of caretaker fall primarily on one person? Who? Does the primary caretaker have family or community support to help them with childrearing? What if the child is born with disabilities, how are they cared for differently than a child without disabilities?
31. In your own words, how are children typically disciplined in your community? Who is responsible for providing this disciplinary action? Are boys and girls disciplined the same? In your experience or in general, do you think children with disabilities are disciplined? The same or different as children without disabilities?
32. In your opinion are children with disabilities more vulnerable to violence and abuse than other children? Please explain. Do you think girls or boys are more vulnerable? What would you do in a case of abuse. Do you know of any laws or policies to follow?
33. *(If time permits: In your opinion, what are the biggest health risks to children under the age of 5 in your community?)*

Impacts of Disability

34. To your knowledge, what services are provided at your health facility and in your community for individuals and families affected by disabilities? Are there services provided by other organizations?
35. Does your health facility have any individuals or specialists who focus on support children with disabilities and their families? How many? What areas of disabilities do they support (ex. physical disabilities, mental impairments, etc.)? Are they available every day or only certain days of the week? Does one need an appointment to meet with these persons? Are there any training or support activities for family to do early stimulation activities in the home?
36. Is your facility equipped with any infrastructure to support persons with disabilities?
37. In your opinion, are persons with disabilities in your community stigmatized, discriminated against, marginalized, or excluded in society? Do you think they also face discrimination when seeking health services at the health facility? In what ways? Are parents of these children stigmatized? Explain (mother and father).
38. How does the care of children with congenital zika syndrome or other disabilities affect the caretaker? Which are the main changes in the life of this caretaker (loss of job, school abandonment)?
39. In your opinion, what more needs to be done to assist persons with disabilities and their families at your health facility? In your community?
40. Do you think amongst health providers there is a potential to have biased attitudes against persons with disabilities? Please explain.
41. Do you think health professionals are equipped to tend to the variety individual and familial needs for improving well-baby care or is there need more training on disability, gender, and gender-based violence prevention?

**USAID APPLYING SCIENCE TO STRENGTHEN
AND IMPROVE SYSTEMS PROJECT**

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

Tel: (301) 654-8338

Fax: (301) 941-8427

www.usaidassist.org