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*Applying Science to Strengthen
and Improve Systems*

TECHNICAL REPORT

Gender Issues Influencing Zika Response in Dominica

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Acronyms

ANC	Antenatal Care
ASSIST	USAID Applying Science to Strengthen and Improve Systems Project
CARPHA	Caribbean Public Health Agency
CDC	U.S. Centers for Disease Control and Prevention
CSaZ	Congenital Syndrome associated with Zika
ECLAC	Economic Commission for Latin America and the Caribbean
FGD	Focus group discussion
GBS	Guillain Barre Syndrome
GDP	Gross domestic product
iDARE	Identify, Design, Apply/Assess, Record, Expand
KAP	Knowledge, Attitudes, and Practices
KII	Key Informant Interview
LAC	Latin America and the Caribbean
MOH	Ministry of Health
PAHO	Pan American Health Organization
QI	Quality improvement
URC	University Research Co., LLC
UNICEF	United Nations Children's Emergency Fund
UNFPA	United National Population Fund
USAID	US Agency for International Development
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 the effectiveness, efficiency, client-centeredness, safety, accessibility, and equity of 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 Dominica 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.

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 Dominica, includes information gathered from patients and healthcare providers in four health facilities. A total of 52 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:

- Focus group participants demonstrated high awareness of Zika transmission by mosquitos but little awareness/knowledge about sexual transmission;
- Caring for children with disabilities can create additional stressors for families, particularly financially, and services for persons with disabilities are limited;
- Male and female focus group participants reported that men generally avoid engaging with the health system unless they are gravely injured or ill, and it is rare for men to participate in antenatal care or well-baby care appointments with their partners;
- However most men are present at the birth of their child, which provides a key opportunity to educate men on how they can participate in their child's development;
- Women are increasingly participating in the labor force at almost equal rates as men (particularly during the reproductive age period), and yet they are still responsible for the majority of domestic work and childcare tasking them with a double burden.

Using these findings, recommendations were formulated focused on engaging men across the spectrum of antenatal, child, family, and personal health services; creating services for children with disabilities and their caretakers; collecting data on disabilities; and developing more gender sensitive and socially inclusive communication/messaging around Zika. These recommendations should guide the Ministry of Health (MOH) in preparing the health system to handle future disease outbreaks and to continually provide quality care for the people of Dominica.

I. INTRODUCTION

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 evidence. 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.

ASSIST achieves improved capacity by supporting Ministries of Health and Social Security Institutions in the Dominican Republic, Ecuador, El Salvador, Guatemala, Honduras, Jamaica, Nicaragua, Paraguay, Peru, St. Vincent and the Grenadines, St. Kitts and Nevis, Antigua, and Dominica to:

- Increase knowledge of Zika risks and prevention measures among health care providers and clients, such as the use of condoms in preventing sexual transmission of Zika during pregnancy.
- Improve clinical screening for signs and symptoms of potential Zika infections during pregnancy and implementation of recommended care.
- 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
- Strengthen the provision of quality psycho-emotional support services for women and families affected by Zika [1].

Since 2018, the USAID ASSIST Project has been working in Dominica to support local actors to improve the capacity of health service providers to deliver consistent, evidence-based, respectful, high-quality Zika-related care with a focus on pregnant women, newborns, and women of reproductive age. Implementing activities are focused on improving service delivery in newborn and child health 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 selected 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 USAID ASSIST Project. This aligns with USAID's **Gender Equality and Female Empowerment policy** to integrate gender in its programming and meets the need of Dominica's **National Gender Policy and Action Plan (2006)** to reaffirm its commitment to gender equity and establish a strategy to mainstream gender.

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 [2]. The *Identify* and *Design* steps 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 of this approach involve closer examination and evaluation, so the process can be adjusted to ensure continued effectiveness and improved development of 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 and in line with the first step, *Identify*, WI-HER conducted a gender assessment 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 assessment was comprised of six Focus Group Discussions (FGDs) (two with pregnant women and women with children under five years, one with men, and three with a mix of men and women), and 14 key informant interviews (KIIs) with health

II. BACKGROUND

A. Dominica Sociodemographic Overview

The Commonwealth of Dominica is an island between the Caribbean Sea and the North Atlantic Ocean, situated south-east of Puerto Rico and north of Venezuela. The island is 751 square kilometers and home to 73,925 people [3].

The country is largely composed of persons from black ethnic and racial groups and also includes mixed race, East Indian, European, indigenous, Hispanic and white individuals. English is the official language, but other languages include Creole and French patois [3].

Dominica, along with other neighbors from the Eastern and Southern Caribbean region, has recently experienced advances in human development, including universal access to primary education for boys and girls, lower infant and child mortality rates, higher life expectancy, lower fertility rates, and overall improved access to health care. However, the region has also experienced increasing rates of unemployment, income inequality, and stagnating economic growth [4].

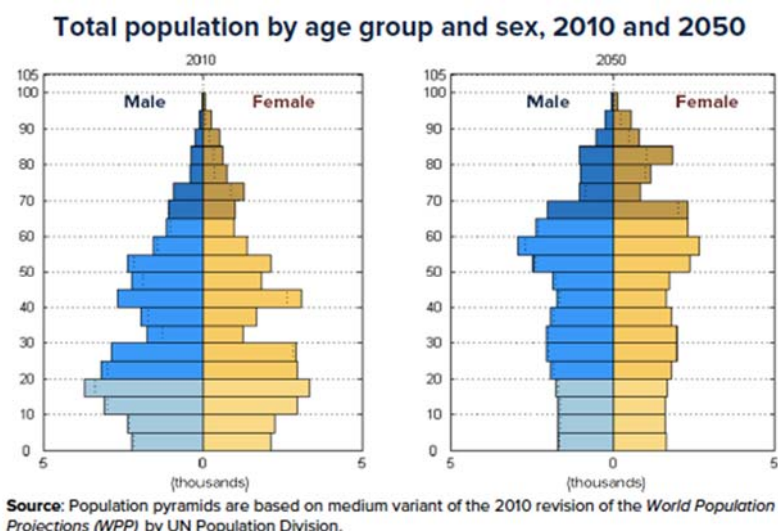
While 96% of births in Dominica are attended by skilled health staff, the infant mortality rate is 31.2 per 1,000 live births (significantly higher than its neighboring countries with rates of 5.1 in Antigua and Barbuda, and 15.2 in St. Vincent and the Grenadines.) Dominica also has a much higher maternal mortality ratio of 110 per 100,000 live births (compared to 53.5 in St. Vincent and the Grenadines) [3]. Dominica is the only country in this area to experience an increase in mortality rates among groups of neonatal babies (from 15.5 to 27.3), infants (from 17.6 to 31.5), and children (from 19.4 to 24) from 2009 to 2017 [3].

In terms of population demographics, Dominica has a stationary population pyramid, typical of countries with a declining birth rate and relatively low death rate (see **Figure 1**). According to the United Nations Population Division and UNICEF, there were 6,100 children under the five in 2012, or 8.5% of the total population [5]. According to more recent 2019 data from the United Nations Statistics Division, around 22.9% of the total population is under the age of 15 [6]. In addition, there are more men than women in the population of Dominica, with a sex ratio of 1.040 (1,040 males per 1,000 females) which is higher than the global sex ratio (1.016) [6].

Although Dominica is considered an upper middle-income country, its GDP of USD\$496,727,000 per year is nearly half of some of its neighbors. In 2017, Dominica's GDP growth rate was -9.5% in large part due to the devastating consequences of Hurricane Maria. Dominica also has one of the lowest GDPs per capita in the region at USD\$ 6,719.3 and is below the Latin America and Caribbean regional GDP per capita of USD\$9,274.8 USD [8,9]. Unemployment remains high, specifically for youth (39.9% among 15-19 year olds and 22.2% among 20-24 year olds) [10].

In education, women and girls consistently out-perform boys academically. In 2011, 57.7% of girls graduated (or achieved GCE/CXC certificates) compared to 42.5% of boys. This trend was also reflected in students that attained Associate degrees (62.9% were women compared to 37.1% men), Bachelor's degrees (55.6% were women compared to 44.4% men), and Master's and Doctoral degrees (53.1% were women compared to 46.9% men) [10].

Figure 1. Total population of Dominica by age group and sex, 2010 and 2050 [7]



Despite higher female educational achievement, the highest levels of decision-making continue to be male-dominated. Men occupy 87.5% of Parliament seats compared to 12.5% occupied by women; 71% of chairpersons of village councils compared to 29% for females; 59.0% of village councilors compared to 41.0% for women; and 53.6% of managers in the workforce compared to 46.4% for women [10].

All of these issues continue to influence the health of the population and the ability of the government health system to respond to disease.

B. Zika Overview

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 – Congenital Syndrome associated with Zika Virus (CSaZ) in which a pregnant mother passes the virus to her unborn child [11]. CSaZ includes a spectrum of birth defects and developmental delays in children that include microcephaly, in which the skull has partially collapsed, problems with brain development, hearing loss, seizures, vision problems, and challenges with joint and muscles movements [12]. 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 due to its associations with microcephaly and other neurological disorders [11].

The Zika outbreak in Dominica began in mid-March of 2016, and WHO reports show that the virus reached all districts of Dominica. In 2016, there were a total of 1,154 suspected cases of Zika and 79 confirmed cases of Zika. Samples of suspected Zika cases were sent to the Caribbean Public Health Agency (CARPHA) for laboratory confirmation (RT-PCR). There were no cases of CSaZ confirmed in Dominica. Confirmed cases saw a drastic increase in early 2016 and then declined towards the end of 2016. Zika virus transmission continued in 2017, but with less intensity.

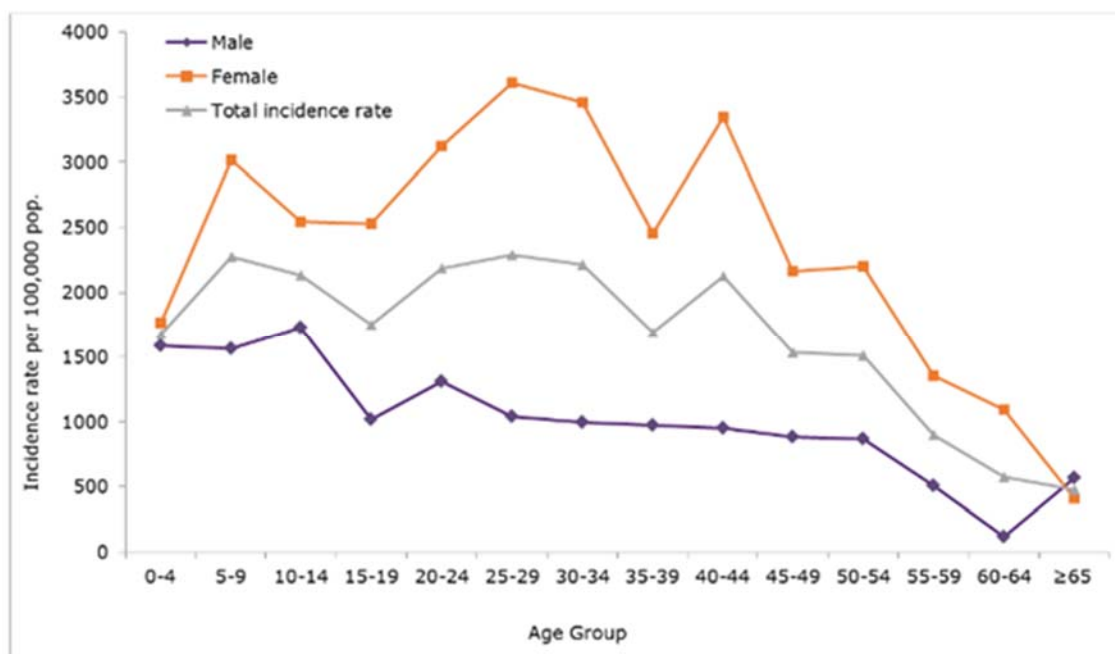
In 2016, ten pregnant women were confirmed to have Zika, with three additional suspected cases [13]. In 2017, six of the Zika-positive pregnant women gave birth: four babies were healthy with no abnormalities,

one died at 24 weeks of gestation, and no information was available for one case [13]. No new or confirmed cases have been reported in the most recent data reported by the WHO and PAHO from January 2018 [13].

Dominica has Zika data disaggregated by age and sex. **Figure 2** shows that higher rates of Zika were observed in females than males in every age group, except for the ≥ 65 age group, and the highest rates were amongst women ages 25-29 [13].

It is unclear whether this gender gap accurately reflects infection rates in the population or whether there is a screening bias. Women in general are more likely to seek care at a health center when sick than men [14], and therefore more likely to be screened for Zika. This is especially pertinent for pregnant women, who were actively advised to be screened for Zika and are more likely to be engaging with the health care system on a regular basis already for prenatal care. In addition, according to Dominica's draft National Zika Preparedness Plan (drafted in 2017), pregnant mothers were especially targeted for information and education interventions. The scarce resources for lab testing was also prioritized for pregnant women during the time of the outbreak, so this can also contribute to the higher rates of Zika in females.

Figure 2. Incidence rate of confirmed cases of Zika virus by sex and group of age per 100,000 population, Dominica (As of Epidemiologic Week 41 of 2016)



Source: WHO/PAHO Zika epidemiological country reports – Dominica. 25 September 2017. <https://www.paho.org/hq/dmdocuments/2017/2017-phe-zika-situation-report-dom.pdf>

While there have not been new cases since 2017, response efforts must be continued and the long-term impacts of the virus (initial epidemic) on populations not overlooked. Some children born to mothers who had Zika virus infection during pregnancy may still be at risk of developing neurological delays as they continue to grow and develop. Due to the challenges in identifying Zika and babies affected by the virus, it is necessary for the health and education sectors be able to provide appropriate and continuous support for families who may have been missed and who will need services in the future. Children affected by the developmental disabilities caused by CSaZ will need long-term access to health and specialized services. Families will 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 mitigate Zika infection rates, 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 varying needs and behaviors of women, men, boys, and girls.

This gender analysis pulls from community member and health provider perspectives to illustrate important factors to consider in Zika prevention and response initiatives. This is the first analysis of gender issues in the Zika response in Dominica and aims to contribute knowledge and learning in this area.

III. OBJECTIVES

The objective of this analysis was to identify key gender-related barriers and gaps that influence newborn and well-baby care systems with a focus on monitoring child development and providing care and support of babies and families with neurodevelopmental issues, including those potentially affected with Zika. The specific objectives of this gender analysis were to identify gender-related and social-inclusion barriers and gaps, best practices, policies, approaches, and opportunities related to family dynamics and well-baby care in the context of Zika in Dominica and to make recommendations to integrate these factors into current and existing programs in order to improve well-baby care programming

IV. METHODS

To achieve the objectives, the analysis team used a mixed methods approach to conduct the gender analysis. Mixed methods assessments 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; (2) key informant interviews (KIIs) with 14 health providers; and (3) 6 focus group discussions (FGDs) with a total of 38 participants. These data were analyzed independently and compared across data collection modalities to triangulate the results.

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). 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.

Dominica-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 **Annex 1** and **Annex 2**) were developed based on the objectives proposed by the ASSIST team and the Ministry of Health of Dominica and supplemented with findings from the desk review.

The FGD guide was piloted in Roseau with groups of fathers, mothers (women of reproductive age), and pregnant women, and the KII guide was piloted with a nurse midwife. The same FGD guide was used in all three populations to try to understand the perspectives of individual participants along with their perceptions

about how these factors play out in society more generally. No substantive changes were made as a result of the pilot, and therefore the results of the pilot FGDs and KIIs were included in the final analysis.

C. Selection of Assessment Sites

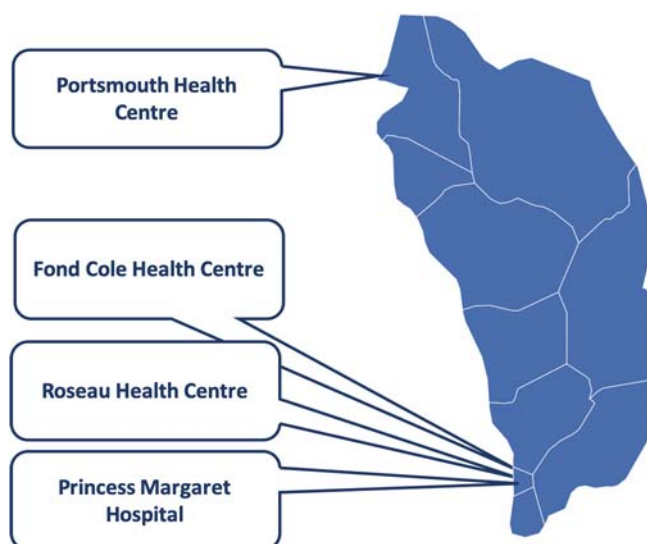
For the assessment, the Dominican Ministry of Health staff selected four health facilities around the capital, Roseau, and in the northern city of Portsmouth, based on site diversity and programmatic impact (see **Figure 3**). At the time of the assessment, the USAID ASSIST Project had been implementing quality improvement activities in these facilities for eight months, building the capacity of health providers to improve newborn and well-baby care, specifically focused on assessment of babies with suspected or confirmed CSaZ, to screen infants at birth for microcephaly.

The selected sites were:

1. Roseau Health Center: a district level health clinic in the capital and central business district of Dominica.
2. Fond Cole Health Center: a community level health clinic about 15 minutes outside of the capital.
3. Portsmouth Health Center: a district level health clinic on the northwest coast of the island in a peri-urban region that was the original capital of Dominica (before it was moved to Roseau).
4. Princess Margaret Hospital: a central level hospital where the majority of babies on the island are born and that has the most specialized care available in the public health system on the island.

This variation of sites allowed for different perspectives from across the island and at both levels of the health system (district health center and central hospital).

Figure 3. Map of data collection sites



D. Sample Size

Sample size was calculated based on data saturation estimation when repetition and redundancy are observed in the data. The investigated team calculated that one to three FGDs per site, with 6-12 participants each, would be sufficient to elicit relevant variation in the themes of interest.

E. Participant Selection

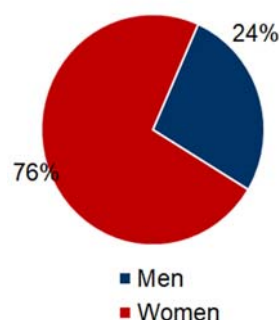
FGDs with community members were stratified according to gender, pregnancy status, and community role. These strata included currently pregnant women, women with children under five (some of which were pregnant during the Zika outbreak), and fathers. Some focus groups were conducted with men and women separately, and some were mixed in order to solicit a broad range of perspectives and dynamics. For the majority of FGDs, the nurse selected participants through convenience sampling, extending invitations to interested participants known to the project or to clients in the waiting room at the facility. Pregnant women were invited to participate in the FGDs before/after their antenatal care appointments, some women of reproductive age were recruited from the in-patient department, and the hospital waiting room. FGDs with men in Roseau were recruited through community leaders who referred potential participants to the investigation team. All participants approached in the waiting rooms were asked if they were interested in participating and informed that their participation would not conflict with receiving the health service for which they came.

Figure 4 and Figure 5 provide detail about participant characteristics for the six FGDs.

Figure 5. Focus Group Discussion Characteristics

Health Facility	FGD Participant Categories			Total
	Pregnant women	Women with children under 5	Men	
Total (#)	19	10	9	38
Total (%)	50%	26%	24%	100%

Figure 4. Gender Distribution of Focus Group Participants



KII participants were health providers and administrators from the district and central levels, and teachers of children with disabilities. All KII participants were women. Participants included:

- Nurse Supervisors (2)
- District Nurse-Midwives (2)
- Primary Care Nurse (1)
- Community Health Aide (1)
- Pediatrician (1)
- Obstetrician/Gynecologist (2)
- Nurse Midwife (1)
- Intern (1)
- Health Information Officer/Statistician (1)
- Teachers of children with disabilities (2)

F. Data Collection

From May 8-13, 2019 the WI-HER/ASSIST team conducted six FGDs and 14 KIIs. Data collection team members were experienced qualitative researchers and were familiar with Zika and health systems in Dominica. Regional team members from the St. Vincent and the Grenadines' Ministry of Health were also present to assist with data collection. Participants provided written informed consent before the beginning

of the focus groups and interviews and signed a consent form before audio taping. Each participant was given a copy of the consent form for their records. All discussions were audio recorded.

The team used a structured FGD guide, exploring general knowledge about Zika before asking questions about gender norms, family economics and decision-making, child care and long-term care, and the impact of disability.

FGD data collection took place in a conference room in each health facility. All rooms were private with only facilitators and participants present so participants could speak freely. FGD duration ranged from half an hour to an hour and fifteen minutes.

The KIIs also used a structured guide focused on gender norms, family decision-making, child care, and available services for children with disabilities. Interviews were conducted in private offices and lasted 30 to 45 minutes.

G. Data Analysis

The team that collected and analyzed the data was familiar with Zika and the Dominican context. Multiple team members analyzed the textual qualitative data, themes were compared, and aligning themes were more thoroughly examined.

V. GENDER ANALYSIS FINDINGS AND DISCUSSION

A. Knowledge about Zika

While almost all participants had heard of Zika, most of their knowledge was surface level and incomplete. Most people cited mosquito-borne transmission of Zika and that it was linked with developmental issues in children born to women infected with Zika during pregnancy, specifically focusing on the size of the head.

“I know about Zika ... but we never went into depth.” (Woman, Fond Cole Health Center)

These findings align with previous knowledge, attitudes, and practices (KAP) surveys conducted by the Dominica Red Cross Society collected using Open Data Kit (ODK) on mobile phones in July 2018. Out of the 103 surveys collected, no one knew that Zika was sexually transmitted, and only 32% of participants knew that an unborn child could be at risk of abnormal development due to Zika infection during pregnancy [15].

Some participants confused symptoms of Zika with the common flu or a cold, citing a runny nose or coughing, or confused Zika with the outbreak of Chikungunya. Not a single participant cited sexual transmission of Zika, the asymptomatic nature of the virus, or the possibility of Guillain-Barre syndrome. In addition, none of the participants said they knew anyone who had Zika during the outbreak or had a child with CSaZ. It's unclear whether this is because the outbreak was limited in Dominica and the Caribbean, there were an even smaller number of confirmed cases, too much time has passed, or if there is some sort of stigma associated with Zika.

In terms of gendered knowledge about Zika, women were more likely to share information they had heard about Zika compared to men. Men were more likely to share that they did not pay attention to health warnings during or after the outbreak.

“I don't really pay much attention to it.” (Man, Roseau Health Centre)

When asked about whether women or men are more concerned with Zika, some women claimed that women, in general, are more concerned since they are or can get pregnant.

“I believe the woman is more concerned, especially if she's pregnant.” (Woman, Portsmouth Health Centre)

However, the majority of participants expressed that both men and women are equally concerned with Zika focusing on the health of their children and that it's not a gendered perspective. Zika was not considered a specific woman's issue.

“My wife was pregnant at the time, so I was concerned. I was worried. I want my son to be healthy, a healthy baby.” (Man, Fond Cole Health Centre).

“Both groups [men and women] were concerned, you never know what kind of effect it will have on you and your children over the long run.” (Woman, Fond Cole Health Centre)

Most participants said they learned about Zika from television or the radio. More women than men reported learning about Zika from a health facility, either from a health provider or from posters displayed at the facility. This could be because women interact with the health system more often than men. Only one of the health facilities during the time of the analysis displayed a poster about Zika prevention featuring a pregnant woman, with no mention of condom use as a prevention method.

These findings highlight the need to disseminate more information about Zika, especially to men, through different communication strategies, including at the community level. It is critical to include messages that highlight that Zika can be sexually transmitted and its asymptomatic nature to promote safe sex practices during pregnancy and imagery that promotes participation of all family and community members.

B. Disability and Social Inclusion

As previously mentioned, Zika infection during pregnancy is associated with a spectrum of birth defects and developmental delays in children known as CSaZ. These include microcephaly in which the skull has partially collapsed, problems with brain development, hearing loss, seizures, vision problems, and challenges with joint and muscles movements [12]. In the long term, these conditions may lead to problems progressing in speaking, learning, moving, and playing. While there have been no deaths associated with Zika or confirmed cases of CSaZ in Dominica, there may be a cohort of children who were born during the outbreak affected by the Zika that will need specialized services, resources, and home care needs. These children may need additional tests, exams, and therapies from various specialists; some of which may be difficult to reach or find. The family may also require the assistance of a social worker, insurance provider, friends, and other family and community members to help with transport, care, and services. Looking at long-term care, it is evident that raising a child affected by Zika can come at a high financial and social cost [16]. Given these potential barriers, it is important to take a deeper look to understand how the community perceives people with disabilities, and particularly children with disabilities, what challenges their caretakers may face, and what kind of services they have access to.

None of the participants in any of the focus groups had known anyone with Zika or any children with CSaZ, so the investigators applied a broader definition of disability (including mental and learning disabilities like autism and Down’s Syndrome, and physical disabilities like blindness and deafness, among others). Even then, very few participants knew of children with disabilities because they are still relatively rare. A 2013 UNICEF survey in 12 Caribbean countries reported that children with disabilities accounted for 1.2% of the children’s population (and 0.3% of the national population) in Dominica, but these numbers could rise as a result of the recent Zika epidemic [17].

1. Perception of People and Children with Disabilities

In Dominica, children affected by Zika may face stigma and discrimination in the home or from their wider community. When asked about children with disabilities, almost all participants were sympathetic but very few had any significant knowledge about interacting with people with disabilities. Only one or two participants mentioned that they had a relative with a disability or a person with disabilities living within their community. Participants that did comment, mentioned that often times families try to hide people with disabilities away from the community or keep from participating fully in society, like in school or having outside relationships.

“The way societies deal with people with disabilities – put them in a room, not knowing that bringing them out or treating them normal will help.” (Woman, Roseau Health Centre)

“People thought [my cousin] was disabled that she shouldn’t experience certain parts of life like having a boyfriend or pregnancy. The community talks, they think disabled people are not normal so they should stay behind the curtain.” (Woman, Princess Margaret Hospital)

“Parents still hide the [disabled] children, sometimes the neighbors say ‘this child has been here all these years,’ and we never know.” (Teacher, Roseau)

These findings also align with previous data from the Economic Commission for Latin America and the Caribbean (ECLAC) and other studies in the region that report that children with disabilities are generally excluded from normal activities within the home and do not participate in community life. While these reports found that families often shun or mistreat their disabled children or that an ‘ugly’ or a disabled baby may be regarded as less desirable and can mean shame for the family, we did not find evidence of these feelings within the focus groups or interviews [18, 19].

To provide more context, investigators also sought out teachers who worked at a school for children with disabilities in the capital, Roseau. These teachers had more insight into working with parents of children with disabilities and grappling with public perception and stigma. One teacher recounted how stigma, and a general misunderstanding of what a disability is, can permeate into broader institutions like the education system. Children are tested in primary school for learning and other kinds of disabilities and are referred to special schools when appropriate. However, even administrators from primary schools were discouraging parents from enrolling their children in the special school, citing that it would make their disabilities worse.

“Some parents said that the principal of the primary school told them not to bring the child here [school for disabled], that it would make them more retarded. There is a lot of misunderstanding and stigma.” (Teacher, Roseau)

Teachers also mentioned that in some instances, families choose not to enroll their children in the school for disabilities because they face pressure from extended family not to.

“We have a list from the Ministry [of Education] of children with disabilities, but some parents don’t show up with their kids. They get pressure from family members to not bring them in ...” (Teacher, Roseau)

2. Perceptions of Challenges of Caretakers of Children with Disabilities

Several female focus group participants mentioned that women may feel pressure from society to have healthy children and may take the blame for their children’s illnesses or disabilities. Parents, and particularly mothers of children with disabilities or developmental delays, may blame themselves for any perceived negative health results of their child.

“Some women take it differently – they ask “what happened, why did this happen, is it a curse? Is it my fault or not? They feel like it’s their fault.” (Woman, Roseau Health Centre)

Focus groups participants also mentioned the need for parents of children with disabilities to seek help and support. They acknowledged that caretakers can face emotional strain and lack the support to cope with the demands of caring for a child with severe disabilities.

“They don’t know what to do, they feel stigmatized. They should seek counseling to deal with the situation from the church or the health care system.” (Woman, Roseau Health Centre)

Several female focus group participants mentioned the financial burden of caring for children with disabilities. One health provider, who worked with children with disabilities, commented on the financial challenges that caretakers, and particularly mothers, must make.

“If she has a disabled child, she won’t be able to work. If she is not able to work, the father may or may not be helping, she might not be able to pay for medical treatment, especially if it requires surgery.” (Health provider, Portsmouth Health Centre)

Although there is universal health coverage for children under 16 years of age in Dominica, there are still extra costs for tests, scans, procedures, and medication. Children with CSaZ may require a host of recurring tests and medication that could compound financially. In addition, children with CSaZ or affected by neurodevelopmental challenges often need physical therapy, cognitive stimulation therapy, and extra assistance with everyday activities. In these situations, primary caretakers are often unable to work outside the home or spend time on non-caregiving pursuits, like education. This isolation from the workforce increases the risk of persistent or worsening poverty [20, 21].

The teachers that were interviewed mentioned that parents may have little information about their child's disability and have difficulties coping, disciplining their children, and understanding what medication or health services their children may need. In addition, they may lack the full support of their extended family due to the stigma which exacerbates many of the aforementioned challenges to caretakers.

"The parents can't even explain to you what their disability is, we are the ones that are discovering and giving them recommendations." (Teacher, Roseau)

"There was a recent incident where the father was so abusive, that he gave his son a beating on the mouth. The child does not understand what he did wrong, discipline should be suitable for the children." (Teacher, Roseau)

"We have a mother here, she had so much difficulty giving her [disabled] son his medication, so we help out. She was so relieved that we were helping, she didn't have family support." (Teacher, Roseau)

3. Services for People and Children with Disabilities

Health providers shared that there are limited services for children and people with disabilities available in Dominica. They mention that there is a referral system from district clinics to Princess Margaret Hospital (Dominica's largest hospital located in Roseau) and support to send patient to other islands for treatment if it is not available in Dominica.

"There is a referral mechanism in place to deal with cases [of birth defects] that cannot be dealt with in Dominica, we refer them to Martinique for management.... There is a lack of specialists here. We can do head ultrasounds, X-rays ...CT scans of the heads, but that's it. We don't have neurologists or neurosurgeons, no ophthalmologists for neonates, which is particularly a challenge for premature babies." (Health provider, Princess Margaret Hospital)

However, the three private schools for children with disabilities and health specialists like pediatricians are only available in Roseau. Families living on other parts of the island are not able to regularly access services or end up paying more for private services.

"We have a list from the Ministry [of Education] of children with disabilities, but some parents don't show up with their kids ... Sometimes it's the distance – kids can't come from the northern part of the island." (Teacher, Roseau)

"There isn't a pediatrician here [Portsmouth] in the public system. There is a private one down the road or you would make an appointment at the Princess Margaret Hospital – they have to find transportation." (Health provider, Portsmouth Health Centre)

The teachers interviewed mentioned that there are linkages between the health system and schools for children with disabilities, however these appear to be limited and with much of the burden placed on teachers.

“Under the health care, the nurses come in and give a physical, mental, vision, and hearing check – sometimes they discover new things, one kid didn’t know they had a heart problem. We teachers take notes and then follow-up with parents ‘have you gotten the test?’” (Teacher, Roseau)

There is some financial support available through the welfare system, but parents don’t have much psychosocial support.

“Social services like welfare are available to assist parents when they have disabled infants, but there are no professional institutions.” (Health provider, Princess Margaret Hospital)

“We have a parent support group We encourage the parents to meet once a month. It’s a time for them to talk, not structured, more of a social gathering.” (Teacher, Roseau)

4. Gender and Disability

During a FGD, teachers report that they see more boys with mental and learning disabilities than girls by a significant amount (80-90% are boys), much higher than expected given global sex ratios [22].

“Out of 35 of our students, only five girls, 90% are boys. More boys have mental disabilities than girls. We’ve always known that it’s a trend – autism and learning challenges affect boys more.” (Teacher, Roseau)

It is difficult to determine the expected sex ratio of disabled children in Dominica because the MOH does not track data on disability. However, data collected by ASSIST on infants that are appropriately monitored and screened for development at their age, and those that are identified with suspected development delays, have comparable numbers across male and female infants. Therefore, more research is warranted to understand this problem.

In reference to differential treatment of children with disabilities based on gender, UNFPA’s 2018 global report on young persons with disabilities reports that in some countries girls with disabilities are marginalized in that they are less likely to receive care and food in the home and are more likely to be left out of family interactions and activities. They are less likely to receive health care or assistive devices than are boys with disabilities. However, the UNFPA’s findings are inconclusive in Dominica, and there was no evidence in the focus groups or interviews that suggested that there was differential treatment of children with disabilities based on gender [23].

C. Norms and Beliefs

Norms and beliefs can materialize in many ways and have a profound impact on a variety of health outcomes. In the context of Zika and well-baby care, this analysis explored expectations about fatherhood and motherhood.

1. Fatherhood and Motherhood

During FGDs, participants were asked what makes a “good father” and a “good mother”. **Figure 6** summarizes female and male perspectives about their roles and responsibilities. The salient characteristic of a “good father” expressed by both men and women was to be a provider for his family - financially but also being a source of security and leadership. The word most commonly used to describe mothers was caretaker. Participants shared the idea that women give love and attention to everyone in the family and ultimately do whatever is needed. Patient is another word that repeatedly came up to describe mothers as a sort of feminine virtue that made them more suited to taking care of kids.

Increased involvement by fathers in childcare has been linked to improved health outcomes, academic performance, mental health, and social skills in children. When fathers have positive relationships with their children, the children are less likely to be delinquent or use drugs, and more likely to live longer, be more productive, and generally have happier lives [24].

Figure 6. Perceptions of Motherhood and Fatherhood

	Fatherhood (provider)	Motherhood (caretaker/everything)
Female perspective	<ul style="list-style-type: none"> • Provider, security, contributes financially. • Supporting, committed, spends time with children, available, caring. • “He shows interest in your babies.” (Woman, Portsmouth Health Centre) 	<ul style="list-style-type: none"> • “Mom does everything, gives love and attention, doesn’t get a lot of sleep.” (Woman, Fond Cole Health Centre) • “She’s a seamstress, football coach, teacher - mother is everything.” (Woman, Portsmouth Health Centre)
Male perspective	<ul style="list-style-type: none"> • “Always provide.” • Respect in the household. • Demonstrate leadership skills, in the family and community. 	<ul style="list-style-type: none"> • “Mothers are more patient, they are with the children more often than we are.” (Man, Roseau Health Centre)

D. Participation

1. Male Participation in Health Care, Domestic Labor, and Child Care

FGD and KII participants affirmed that men do not engage with the health care system as much as women do, reaffirming a trend that is witnessed in many parts of the world [14,25,26].

“Men in Dominica won’t go to the clinic unless they are in a lot of pain – they don’t like to accompany their partners or go into the health center.” (Man, Roseau Health Centre)

“The men have to be dying to come into the clinic – only the women and children do so.” (Health provider, Fond Cole Health)

“They don’t like to hear bad news. No news is good news.” (Man, Roseau Health Centre)

These quotes all imply that men have to be experiencing a severe health problem to warrant a visit to the doctor and that it is not the norm for men to accompany their pregnant partners for antenatal care or well-baby care visits. A notable exception mentioned by a health provider in Portsmouth was that men who had immigrated recently from Haiti were more likely to accompany their partners at health centers. The health provider shared that this is because their partners speak Creole and need extra support in translating and navigating the health system during their appointments.

This also ties into expectations about men being the main providers for their households and so they are more restricted by their work schedules.

“Many of the men are the breadwinners and they have to be at work, but the mothers work as well, and they find time to come in.” (Health provider, Portsmouth Health Centre)

Some women insisted that even if men did not have restricted schedules, they would still avoid the health system because they view it as a woman’s responsibility.

“It’s a woman’s job, to them.” (Woman, Fond Cole Health Centre)

“Men don’t have the patience to wait (in the health center), it agitates them.” (Woman, Roseau Health Centre)

The idea of patience comes up again here as a quality that men do not possess and therefore makes them ill-suited to deal with situations that are either unpleasant or difficult such as health care and child care. Most men in the focus groups said they don’t take their children into the health center when they are sick because they have to work, but often they will pay for the bill. However, one woman said that she works, pays for the bill, and takes her child to the hospital.

“I work, so I take the children, I cover their medical expenses as much as I can.” (Woman, Roseau Health Centre)

Because this mother works, she has the money to be able to pay for her child’s medical care, and it is still her responsibility to take her children to the doctor. Even though men are less likely to engage with the health system in general, the majority of fathers do attend the birth of their children.

“[During birth] fathers have a chance to dress the baby, 99% welcome the opportunity. They understand the importance and they like it, they take pictures with their babies ... ‘Do you want a stranger to dress and feed your baby for the first time?’ They need to be encouraged.” (Health provider, Princess Margaret Hospital)

“Quite a few of them are interested in how to care for the baby, when the mother has to take a shower they can take care of the baby if it is crying ... We need more promotion and more education geared towards men.” (Health provider, Princess Margaret Hospital)

Therefore, childbirth is a crucial opportunity to begin to involve men and encourage them to actively participate in taking care of their baby by sharing information with them and showing them how to dress and change their babies.

Descriptive research of child care practices across the Caribbean is limited, but an early childhood report found that despite stereotypes of extended Caribbean families, mothers are providing an increasing proportion of care for children [27]. According to the report, a mother’s load is often eased by help from a father, or from other relatives such as aunts or grandparents; but despite the importance of other family members and the growing role of men in child care, the majority of the responsibility for children falls upon women. Additionally, friends and neighbors have become less willing to look out for other people’s children and in some cases, leaving children with friends or neighbors is frowned upon in a way it was not before. Compounding limited care support networks, Caribbean mothers express they have a more demanding role than in previous generations. The report found that mothers took pride in their role but also stressed that it is a full-time and demanding one.

During this gender analysis, FGD and KII participants reaffirmed that the mothers were usually the primary caretakers, but they also mentioned that grandparents, older siblings, or other female relatives provide child care support. Daycare was referred to as another option, but often seemed to be a last resort if no one else was available to help them with child care.

“If one kid is sick all of them are sick, that’s why I don’t take them to daycare, and they are expensive.” (Woman, Roseau Health Centre)

“A woman would use daycare if she had to go back to work, her maternity leave is finished, and no family to help. Everyone is busy these days.” (Woman, Princess Margaret Hospital)

The quality of daycare is especially important to consider as the culture in Dominica shifts away from ample community support to raise children to more individual responsibility where working mothers often carry the majority of the burden.

2. Women’s Participation in the Labor Force

Women in Latin American and Caribbean countries already face challenges and inequality in comparison to men with regards to the careers they have and the wages they earn. Women tend to be in less stable, less desirable, and lesser-paid jobs compared to men [28]. In Dominica, women have made substantial progress in the labor force though males still comprise the majority in managerial occupations such as legislators, senior officials, and managers (53.6% male compared to 46.4% female). Female participation has grown in professional fields (34.4% male compared to 65.6% female) as well as in the technical and associate professional fields (47.8%: male compared to 52.2% female). Sales and services are dominated by women (36.9% male compared to 63.1% female), and so are clerical workers (21.9% male compared to 78.1% female). Crafts and trades such as building construction, metal and machinery trades, food processing, and wood work are still overwhelmingly male (91.9% male compared to 8.1% female) along with skilled agricultural and fishery workers (85.0% male compared to 15.0% female) [10].

Women are also often pushed into un- and under-paid domestic work, which not only limits their ability to be economically independent but also reinforces a patriarchal hierarchy [29]. Furthermore, women participating in the informal economy who have jobs that are not formally registered are often faced with fewer social and economic protections.

demonstrates that women participate in the labor force almost as much as men do in Dominica based on data from 2013. The smallest gap between male and female participation in the labor force is observed during the crucial reproductive and childbearing years between the ages of 25-45. So precisely during the period when women are the most likely to be responsible for the majority of childcare, they are also participating in the labor force at rates very similar to men.

Figure 7. Labor force participation by age group and sex, Dominica, 2013 [30].



Source: Commonwealth of Dominica Central Statistical Office (2016)

E. Access to and Control of Resources

Who has control of and access to money and resources in the household is often an important indicator of power dynamics and a predictor of a child’s health. A 2016 Save the Children report on gender inequality in Latin America and the Caribbean reported that women’s decision-making power in the home influences the health and nutritional resources dedicated to children, such as feeding practices, prenatal and birthing care, and treatment for childhood illness and immunization [27]. Additionally, women’s access to and control of resources for their own health and well-being have a significant impact on their children’s survival, health, and nutrition [27]. With domestic and care-taking work often falling to women as detailed below, it is

important to consider how care roles can influence the health status (and health progress in the context of Zika) of a child.

Both male and female participants in focus groups mentioned that mothers and fathers contribute to and have access to money in the household, which reflects the broader trend of more women entering the labor force. Even if the man is providing the majority of the financial resources, participants explained the woman is also involved in decisions about how it gets spent.

“The bills belong to the men because we are the breadwinners. It’s a cultural thing – women do the shopping, the food, the clothes, etc. – I pay the bills and contribute to food, but it’s a mutual decision.” (Man, Roseau Health Centre)

Participants almost unanimously said that women often manage the money, decide what food and household necessities to buy, and put aside funds for household savings.

“My husband gives me the money to hide away, I set funds aside like a piggy bank. We women know to stretch things ... Tell us exactly what you’re going to do when you get it, if it’s really, really important then you get it.” (Woman, Roseau Health Centre)

F. Patterns of Power and Decision-making

When looking at relationship dynamics, Afro-Caribbean populations experience low rates of legal marriage and high rates of single-motherhood. Specifically, in the Eastern Caribbean, almost 70% of children are born into non-nuclear families [31,32]. Traditionally male dominance and patriarchal norms have permeated these societies and driven expectations of women’s subordination and dependence on men while also charging them with managing family life. However, these norms are shifting, and increasingly women are becoming relatively economically independent in the Caribbean, partially since it is not uncommon for men to be absent from the family unit - either uninvolved or having migrated away from the islands - leading to the creation of many female-headed households.

Some female focus group participants described these traditional household power dynamics, mentioning that men were thought of as the head of the household since they brought in the most money, and in alignment with other religious and cultural-patriarchal values.

“The head of the household is the person who brings in the most income. They have the authority to rule the house. Usually, it’s the man, and the woman and children have to follow.” (Woman, Princess Margaret Hospital)

“Sometimes it’s religious. Sometimes it’s his ego.” (Women, Princess Margaret Hospital)

However, female focus group participants also illustrated that view has been increasingly changing as more women enter the workforce, earn more money, and manage the household finances and activities. It was mentioned several times that women are the heads of the household because they know how to manage the home.

“It used to be the man, it was instituted by code, it was the rules, it was in the bible, but that is changing.” (Woman, Portsmouth Health Centre)

“Women are better managers; they know the home.” (Woman, Portsmouth Health Centre)

“If you want to ask the man what’s in the kitchen, he has no idea. If you want to do the laundry, he has no idea.” (Woman, Fond Cole Health Centre)

G. Laws, Policies, and Systems

Focus group and interview participants touched upon several important laws, policies, and systems throughout the analysis that influence child care practices.

Once policy mentioned several times by female focus group participants and health providers, was that **maternity leave** is three months for mothers compared to paternity leave of four days for fathers. Some of the male focus group participants were not even aware that they were entitled to paternity leave, and only one man who worked for the government mentioned that he was able to take paternity leave [34]. This institutionalizes unequal norms about child care and sets up the expectation that it's not as important for fathers to engage in a meaningful way with their child's early development. However, this issue is gaining traction, and new paternal leave policies in private companies are being introduced, including a proposal for 16 weeks of leave for mothers and eight weeks of leave for fathers [34].

Another policy that was referred to several times by health providers was **universal access to health care** until the age of 16. While this is beneficial for families with children everywhere, there remains several hidden costs through additional tests, specialists, and medications. This can be particularly burdensome for families with children with disabilities that may require regular and repeated testing, screening, and medication.

"Medicine wise, it's supposed to be free, but you are prescribed a medication that is not available at the pharmacy, you have to go private; it costs money." (Woman, Princess Margaret Hospital)

When discussing female participation in the labor force and the shifting cultural norms about power dynamics and division of care in the household, one female focus group participant mentioned the **National Employment Programme** (2010) [35] as a key driver of developing opportunities that have increased female employment over the last decade.

"Lately women are taking jobs traditionally done by men, like driving a bus. Through the National Employment program, more females are doing what the men did back in the day." (Woman, Princess Margaret Hospital)

While several systems are in place to address the Zika outbreak and its consequences, data collection systems are particularly important to improve surveillance of Zika, well-baby care, and children with disabilities. The MOH in Dominica collects data on nutritional status and stunting, but nothing on mental disabilities. This makes it difficult to count and track the prevalence of disabilities and adequately allocate resources. Strengthening data collection systems, building capacity of health providers to collect this data, and strengthening linkages between the health system and the educational system to continue to monitor and identify children with disabilities are essential to addressing this issue.

VI. RECOMMENDATIONS

Lessons from the Zika outbreak and findings from this analysis can be applied to the broader health system and maternal and child service delivery to promote self-reliance and prepare the health system for any future outbreaks of Zika, or similar infectious diseases and emerging public health threats. Mainstreaming gender and social inclusion into policies and regulations will promote human rights and integrating gender into service delivery strategies and practices will lead to more equitable and quality services. The following recommendations will not only improve the ability to respond to a future Zika outbreak in an effective way but will also leverage opportunities to improve the health system in general and the quality of maternal and child health services in particular. The recommendations provided in this report are inclusive of those provided by KII and FGD participants and recommendations that the research team deemed important to fill the identified gaps and challenges.

Strengthen services for children with disabilities and their caretakers [11].

- Test and diagnose children with disabilities and provide counseling and education to parents on appropriate development and stimulation.
- Encourage well-baby visits throughout the child care continuum, particularly in the first three years of life.
- Provide ongoing access to training for personnel who work in schools about how to identify disabilities and refer children to services.
- Implement early detection and intervention programs to ensure a smooth transition of children with disabilities to preschools and other education programs.
 - Train more members of the Roving Caregivers Programme (RCP), a home visiting program that focuses on early childhood development in children from birth to three years of age who do not have access to any formal early childhood development programs.
- Provide psychological assistance or counseling to children with disabilities in the school system.
- Provide sensitization training to health and school personnel about social inclusion and disability.
- Support public social behavior change communication campaigns to increase public awareness of disability to reduce stigma and to increase awareness of referral pathways. This should focus on educating the public on available services in the health system and who is eligible for those services. Children and infants with special needs should be navigated through the health and education systems properly to ensure that they have timely access necessary services.
- Improve the quality of daycare to support families of children with and without disabilities.
- Increase access to education at all levels for children with disabilities by mainstreaming children with disabilities into the school system.

Strengthen communication about Zika that is gender-sensitive and socially inclusive.

- Expand messaging to include the importance of early neurodevelopment screening as part of routine well-baby care and its benefits to addressing babies' developmental needs and improving their quality of life.
- Expand current messaging (i.e., posters, brochures, radio and television appearances) to feature men, women, and youth engaging in Zika prevention activities. Focusing solely on the pregnant woman misses an opportunity to empower the family and community to be responsible for Zika prevention.
- Utilize images, photos, posters, and videos when communicating about Zika to make messages easier to understand, especially for non-English speaking populations, and to create a lasting impression. In addition, consider creating Zika prevention materials in Creole and French Patois.
- Ensure that Zika communication materials emphasize sexual transmission, not just vector-borne transmission, and the asymptomatic nature of Zika – an absence of symptoms does not guarantee they cannot infect others.
- Distribute promotional materials (posters, flyers, brochures, etc.) not only at health facilities, but in places that men and youth are more likely to frequent (places of work, schools, recreational facilities, community spaces, etc.)
- Consider online communications through social media (Facebook, WhatsApp, videos, etc.) to reach younger populations.
- Continue to utilize radio and television as media to disseminate information about Zika.
- Consider outreach to schools, for materials and health presentations, to reach youth.

Approach men as clients and engage men in well-baby and child care activities.

- Focus on reaching men as clients of health services with comprehensive information about Zika prevention strategies, but also with strategies for respectful communication and decision-making with their partners.

- When engaging men, promote partnership and co-responsibility to encourage a more active role in child care and domestic labor – for the health and development of their children and the health of their partner.
- If the pregnant woman consents, invite her partner to participate in ANC counseling and well-baby care appointments and promote the active participation of the partner during the appointment.
- When possible, ensure promoters and/or providers of both sexes are available for education and counseling.
- Distribute materials about Zika prevention and best well-baby care practices for pregnant women to take home to their partners if they are not physically present.
- Engage men that are already in the waiting room to provide counseling or presentations about Zika prevention, family planning, well-baby care, etc.
- Reach men through presentations or promotional materials at their place of work, in recreational spaces, in schools, etc.
- Develop a social and behavior change communication campaign to foster long-term, normative shifts in behavior in support of increasing male engagement in well-baby care.
- Most men are present during birth which is a key opportunity for health providers to educate them and encourage them to be more involved:
 - Encourage men at birth to hold baby, skin to skin, and change the baby's clothes;
 - Allow them to watch the cesarean section procedure from the surgical theater so they will understand and be more sympathetic;
 - Use that opportunity to encourage male participation in subsequent well-baby care visits.

Improve scope and inclusiveness of data collection.

- Reinforce the importance of data collection and entry and consider training nurses to enter data directly into computers (although there are connectivity issues at some centers).
- Provide training on how to collect, analyze, and use data, particularly sex-disaggregated data.
- Track and measure data on disability. With an accurate measure of prevalence, services and resources can be allocated appropriately.

VII. CONCLUSION

Evidence presented in this report indicates that the relationships, norms, and behaviors between women, men, partners, families, and health care providers can impact perceptions that influence newborn and well-baby care systems and systems of care and support of babies and families with neurodevelopmental issues, including those potentially affected with Zika. This report provides insights on community perceptions of children and people with disabilities, challenges that family members caring for children with disabilities may have (particularly mothers), including gender care-taking dynamics, and services that are available for people with disabilities. This report also sheds light on important gender norms that have an impact on Zika transmission, diagnosis of Zika-related disabilities, and well-baby care. It identifies some specific entry points to increase male engagement so that women will not carry the entire burden of preventing and responding to Zika.

Finally, this report has helped highlight that although Zika is not active in Dominica, the impacts of the virus are still being identified. As Zika virus was new to the region, little information was known at the onset and height of the spread. With this in mind, it is quite possible that there are cohorts of children and families in Dominica that may not know their child has been affected or that a health challenge present in their child could be a result of previous Zika infection. This message must be recognized by governments, donors, implementing partners, and health care providers so that more families can be identified, entered into treatment, and start additional well-child therapies that can assist with healthy development. Considering gender in Zika prevention and response efforts helps provide more equitable health information and services so that children, families, and communities can be educated, make informed decisions, and prosper.

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APPENDICES

Appendix I: 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.

Objectives:

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?
2. What have you heard?
3. How do you get Zika?
4. What are consequences of Zika virus during pregnancy?
5. Where did you hear it from (TV, radio health center) etc.?
6. Should men and women be equally concerned about Zika or is it more important for women?

Gender

7. What makes a "good" father? What are his responsibilities to his family?
8. What makes a "good" mother? What are her responsibilities to her family?
9. In general, do people prefer sons or daughters?

Family Economics and Decision-Making

Emphasize in general, not necessarily in your household.

10. In general, within the family, who is employed? What type of work do they do?
11. Who in your family works inside of the home (cooking, cleaning, laundry)? What type of work do they do?
12. Who is considered the head-of-household in your family? Why?
13. How are decisions made about spending money?
14. If your entire family is sick, but there was only a limited amount of money, who would receive care first?

Well-Baby Care and Long-Term Caretaking

15. In general, who is responsible for baby care after a child is born? (Mother, father, extended family, neighbor, other member in the community?) Who is responsible for feeding, changing diaper, bathing, watching, putting to bed, playing?
16. 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)?
17. In general, do fathers accompany their partners to antenatal care visits, to the birth, or well-baby care visits?
18. 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?
19. Do you know how to assess if a child is developing correctly for their age group?
20. In your opinion, what are some of the primary stressors and challenges a primary caretaker faces?
21. 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?)
22. If children misbehave, how are they disciplined?
23. 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?

Impacts of Disability

24. Do you know any people who have children with disabilities?
25. In general, how are children with disabilities treated? In general, are girls and boys with disabilities treated the same in their homes, by their families, friends, and community?
26. 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?)
27. In your opinion, are children or persons with disabilities at risk of violence or discrimination? What types of violence? Are boys or girls with disabilities more vulnerable to violence?
28. 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?
29. 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 II: Key Informant Interview Guide

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.

Objectives:

The objectives 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

1. Have you heard of Zika virus? What have you heard?
2. 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

3. 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 healthcare they need?)

Well-Baby Care and Long-Term Caretaking

4. In your opinion, who is responsible for the care of a child with CSAZ or other disabilities?
5. 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.)?
6. When children are born with CSAZ or other disabilities, what are the main challenges faced by the family and the mother (abandonment, marginalization, etc.)?
7. 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?
8. 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?

9. From your perspective, who is responsible for taking care of children in the home? Mother, father, extended family, neighbors, other members 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?

10. 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?

11. 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?

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. 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?

14. 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?

15. Is your facility equipped with any infrastructure to support persons with disabilities?

16. 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).

17. 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)?

18. In your opinion, what more needs to be done to assist persons with disabilities and their families at your health facility? In your community?

19. Do you think amongst health providers there is a potential to have biased attitudes against persons with disabilities? Please explain.

20. Do you think health professionals are equipped to tend to the variety of individual and familial needs for improving well-baby care or is there need more training on disability, gender, and gender-based violence prevention?

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