Puerto Rico Department of Health
Maternal, Child and Adolescent Health Division
Children with Special Medical Health Care Needs Division

Puerto Rico 2020 Health Needs Assessment

Summary

DIVISION MADRES, NIÑOS Y ADOLESCENTES
PO BOX 70184, SAN JUAN, PR 00936-8184
TEL. 787.765.2929 EXT. 4550 FAX 787.294.0726 www.salud.gov.pr

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a. Process Description

The Puerto Rico (PR) Title V Maternal, Child and Adolescent Health Program (Component A & B or MCAHP) and the Children with Special Health Care Needs (Component C or CSHCNP) are essential public health programs that provide and advocate for services for over 42.1% of the PR population (Census International Data Base 2019, CIDB).

The Goals and Guiding Principles of the PR 2020 Health Needs Assessment (2020 HNA) were:

Goals	Guiding Principles
Collect data and evidence to inform the priority needs of the Maternal, Child, and Adolescent (MCA) populations including children with special health care needs (CSHCN).	**Study Feasibility:** Design a study that can be carried out with the available resources and the quality that the population deserves. This is achieved by considering the resources and time available while seeking to safeguard the quality and validity of the information and data to be collected.
Identify PR Priority Health Needs for the MCA populations including CSHCN.	**Target Population:** Women of reproductive age (10-49 years), pregnant women, infants, children and youth (1-21 years) and children and youth with special health care needs (1-21 years) and their families.
Enhance stakeholders' participation in all aspects of the HNA.	**Participation:** Involve MCA populations, families and all interested sectors. **Communication:** Systematically communicate to the MCA community and stakeholders. **Transparency:** Ensure that the decision-making processes based on the findings are clear and understandable to all stakeholders. Promote accountability.
Improve health outcomes for the MCA populations.	**Approach:** Consider assets and gaps, risk and protective factors, and positive outcomes. **Data-driven Decisions:** Use quantitative and qualitative data to inform decision making.
Strengthen collaborations with agencies and organizations working for the wellbeing of MCA population and families, including CSHCN.	**MCAH Community and Stakeholder Integration**: Seek MCA community and stakeholders' experiences and views to inform decisions, efforts and results.

The 2020 HNA used a three-phase framework guided by the socio-ecological model (SEM) and the life course approach. This framework enabled us to link MCA needs, system capacity and prioritization that led to the 5YR Action Plan (priorities, performance measures, outcome measures, evidence-based measures, strategies, and activities).

Phase One: Assessment of the Needs of MCA population groups. Quantitative and qualitative data collection and analysis for each population group: pregnant women, reproductive-age women, infants, children, and adolescents, including children and youth with special health care needs.
Phase Two: Assessment of the Capacity of the System to meet MCA population needs. Assessment of the capacity of the broader system to meet the identified MCA population needs and the strengths and challenges faced by PR Title V in relation to the core MCAH functions.
Phase Three: Setting potential priorities based on the assessment of needs and capacity. Prioritization (narrow down) of potential needs priorities and matching needs to capacity, setting targets, identifying activities and/or actions, and allocating resources.

Stakeholders' engagement was crucial in each phase as they gave input into the research design, survey, and interview guides; shared their knowledge, experiences, and concerns; and actively participated in the prioritization process.

Three interconnected HNA committees focused on the prioritization processes.

HNA Advisory Committee: Composed of stakeholders from the public and private sectors, non-profit organizations, academia, and family representatives from the CSHCN Program, the Home Visiting Program and the Youth Advisory Council. The Committee's task was to discuss HNA findings, rank potential needs, recommend strategies, and give input into the PR State Action Plan 2020-25.

CSHCN Advisory Board: Composed of CSHCN experts from the health and social fields that closely collaborated with Title V in the selection of the state priorities and development of the State Action Plan for the CSHCN domain. This group was organized due to the unique needs and situations faced by the CSHCN population and families. The Board based its decisions on Title V mission, available funds, existing evidence-based practices, challenges, and opportunities as well as CSHCN domain's needs prioritized by the HNA Advisory Committee.

HNA Steering Committee – Composed of the Evaluation, Monitoring, Research and System Development Section (EMRSDS) researchers (SSDI Coordinator, Biostatistician, Epidemiologists, Health Program Evaluator, and Cultural Anthropologist), Pediatric Consultant, Comprehensive Adolescent Health Program Director, MCAHP Director, CSHCNP Evaluator, Title V Home Visiting Program Coordinator and Evaluator, and MCAHP Psychologist. Based on the input from the HNA Advisory Committee, the committee engaged in the selection of state priorities and development of the State Action Plan. This Committee also devised the framework, strategies, and methodologies used in phase one of the Needs Assessment.

The main methods and data sources used to assess the MCA population needs were:

Self-Administrated Survey in HRSA Funded Community Health Centers (FCHCs). To identify MCA population needs in communities according to five categories for each domain: socioeconomic situation, habits and lifestyle, preventive practices, health conditions, and access to services. Surveyed 500 women aged 18-49 years that received services in one of the 33 participating FQHCs. Of these, 83% had the Government Health Plan (GHP) and 1 for every 10 were pregnant.
FCHCs Health Care Provider Survey. To identify the barriers health providers' face to provide services to the MCA population. Surveyed 190 health care providers of the 33 FQHCs: 17% general physicians; 12% pediatricians; 8% family medicine, and 4% OB/Gyns. Other respondents were nurses, social workers, psychologists, case management coordinators and nutritionists
Qualitative Analysis of PRPRAMS Back-Page Comments. To identify the concerns and situations raised by women in their free comments. Analyzed 199 back-page comments from the telephone interviews corresponding to batches 1-8 (2017).
WRA Key Person Interviews. To obtain information based on first-hand experience and observations about the issues impacting the health and wellbeing of PR pre-conceptive young adult women (21-34 y/o). Interviewed seven (7) women staff with no children from the Maternal, Child, and Adolescent Health Division (Central Level).
CSHCN Key Person Interviews. To gain providers' insights into CSHCNs' and families' main needs and the limitations and barriers they face to serve them. Interviewed twelve (12) key persons: 3 pediatricians, 1 general physician, 1 social worker, 3 GIP case managers,1 nurse, 1 speech pathologist/health educator and 2 staff from the Independent Life Movement (MAVI, Spanish Acronym).
Focus Groups and Conversational Meeting. To ascertain the needs of families with CSHCN such as health services' needs, caregivers'/families' needs, and perceptions of the health system's strengths and weaknesses. Conducted seven (7) focus groups in which a total of 35 CSCHN families participated. A conversational meeting with 31 young adults with special health care needs was also held. The meeting was coordinated in collaboration with MAVI.

Other quantitative data sources included: population-based data from PR Vital Statistics (VS); public and NGO agencies providing services to MCA populations on morbidity, lifestyle, screening and risk factors; PR Community Survey, Monitoring the Future, PRPRAMS, Perinatal Period of Risk, Asthma Surveillance System, PR Immunization System, YRBSS, BRFSS, NIS, PR STDs Surveillance System, KIDS Count, IDEA Child Count, PR-CSHCN Survey, MCH-JS, PR Autism Registry, PR Birth Defects Surveillance and Prevention System (BDSPS) Annual Report, and Technology Dependent Children Registry. We also assessed capacity through the CAST-5 Needs Assessment Survey with 49 staff from the MCAH and CSMN divisions: divisions' and regional directors, RCPs directors, managers, consultants, coordinators, family support and health care providers.

b. Findings

i. MCH Population Health Status

A summary of the key findings corresponding to the 25 potential needs (stratified by domains) identified by the stakeholders is presented below. (For graphs and charts see the Attachment: Puerto Rico 2020 Health Needs Assessment Supporting Document).

WOMEN/MATERNAL HEALTH DOMAIN

In 2018 the number of WRA was 812,204 (ACS 2018) that represents 25.4% of PR total population (10-14 y/o: 10.9%; 15-17 y/o: 7.2%; 18-19 y/o: 5.4%; 20-21 y/o: 5.4% and 22-49 y/o: 71.2%). About half (53%) of WRA is covered by the GHP. 2019 Vital Statistics (VS) reports 20,409 live births (LB), a 28% decrease since 2015 (28,335 LB). Most births occur in women between 20 and 34 y/o (78%), followed by women 35 y/o or older (13%) and teens 10 to 19 y/o (9%). 67% of live births are from mothers covered by GHP.

The 5 identified needs in this domain are:

Depression, Stress, And Anxiety

FCHCs Survey. About 30% of respondents identified depression, stress and anxiety as the health condition that mostly affects women. Depression and anxiety were in the top five conditions three months before pregnancy as reported by women who had a LB (PRPRAMS 2017-18). According to PRBRFSS, women 35 to 54 y/o reported that a health care professional told her more frequently that she has depression when compared with the other age groups, still this proportion is decreasing (AAPC: 0.6%) from 2014 to 2018 (24% vs. 23%), while an increase is observed in the other age groups, mostly in women 35 to 44 y/o (19% vs. 21%; AAPC: 4% increase).

PRPRAMS Back-page Comments. Women brought up issues related to emotional health after pregnancy. Mothers of pre-term babies felt sadness, anxiety, and distress. There were women who experienced post-partum depression and expressed the need for more understanding and support.

WRA Key Persons. They pointed out that situations such as fast pace of life, economic responsibilities, combining work and study, and social pressure to have children often leads to anxiety and stress among young adult women (21-34 y/o) with no children.

Communication and Sensitivity of The Provider

PRPRAMS Back-page Comments. Women brought up situations they had faced with health providers (e.g. physicians, nurses, and hospital staff) that caused them disgust. Those situations included unfair treatment, no response to their questions, failure to give them explanations, having a C-Section, and no breastfeeding support from nurses during their stay in the hospital. From their comments, what mothers want is to be listened to, have information, and respect for their decisions.

WRA Key Persons. They all spoke about the need for respectful, sensitive and open communication on the part of physicians as there are those that: a) seldom and/or barely offer explanations; b) scold patients; c) do not allow women to make their own decisions

(informed) regarding procedures and/or treatment. They strongly advocate for what the literature calls “person-centered care” that entails seeing the patients as partners, being responsive to their needs and values, and engaging them in health decision making.

Health Conditions in WRA

FCHCs Survey. About 41% of respondents identified that the preventive practice that WRA perform less frequently is the preventive medical visit that may increase health risks. According to PRBRFSS (2014-18) a significant increase (AAPC: 4.7%; $p<0.05$) is observed in the annual preventive visits in women 18 to 44 y/o. The proportion of women that reports that a health care provider informed that she has diabetes or high blood pressure is also decreasing for all age groups. However, these conditions are more significantly reported ($p<0.05$) by women 35 to 54 y/o when compared to younger women. Preventive oral check-ups are also important during the preconception period. PRBRFSS (2014-18) also reports an increase in all age groups (AAPC 25-34 y/o: 0.3%; AAPC 35-44 y/o: 6.5%; AAPC 45-54 y/o: 2.9%), except in women 18 to 24 y/o (0.2% decrease).

WRA Key Persons. A key issue raised is the need to promote preventive visits among young adult women (21-34 y/o) with no children as they only seek health care when they feel sick. Indeed, they said that working in the MCAH Division made them aware of the importance of preventive visits. Other health related conditions mentioned were unhealthy eating, ETS, asthma and cancer. They also noted that costly health insurance hinders pre-conceptive women’s access to health care.

Health Conditions During Pregnancy

FCHCs Survey. Forty-four percent (44%) respondents identified health conditions during pregnancy as a need of pregnant women. VS 2018 reported that 99.9% of women who had a LB received prenatal care irrespective of the trimester of initiation (83.2% began PNC during the 1^{rst} trimester). Between 2014-2018 VS reports a significant increase of gestational diabetes, preeclampsia, and eclampsia (AAPC: 13.3%, 7.7% & 34.9%; $p<0.05$) in mothers that had a LB during this period. Other conditions during pregnancy that were reported by women with LB (PRPRAMS 2018) were anemia (20.1%), anxiety (12.8%), depression (9.2%) and thyroid problems (4.7%). Oral health during pregnancy is also related to poor pregnancy outcomes. About 43% of women who had a LB reported to visit a dentist or a hygienist for a routine dental cleaning (PR-PRAMS 2018). Women who had a LB mainly reported not having a routine dental cleaning visit because they could not find a dentist or hygienist that would provide services to pregnant women (PRPRAMS 2018: 23.5%).

PRPRAMS Back-page Comments. Women spoke of the importance of “having a healthy pregnancy” to have a healthy baby. A healthy pregnancy is associated with prenatal care and avoidance of risks such as alcohol use and smoking. Women also commented on situations that caused them a great deal of stress, anxiety, and sadness while pregnant such as economic hardships and a high-risk pregnancy.

Nutrition During Pregnancy

FCHCs Survey. About 33% of participants identified inadequate nutrition during pregnancy as a habit that mostly affects this population. PRPRAMS (2017-18) reported

that 92% of women who had a LB received education/orientation of healthy eating habits by a health professional. On the other hand, VS 2018 reports that 36% of women who had a LB had an adequate weigh gain during pregnancy. However, few women reported consuming fruits 5.1%) or vegetables (3.2%) during pregnancy (PRBRFSS 2017). Furthermore, according to the risk factors for WIC enrollment (FY 2017-18), 13.5% of women were underweight (IMC<18.5) and 71.1% was overweight (IMC≥25). For the last fiscal years (2015-16 to 2017-18) a significant increase ($p<0.05$) in women underweight (4.4%) and overweight (6.1%) was observed in women that received services.

PRPRAMS Back-page Comments. Healthy eating including prenatal vitamins was mentioned by women as a key factor to have a healthy pregnancy that can have a positive effect on the baby's health.

PR TITLE V AND WOMEN/MATERNAL HEALTH: The domain's needs are summarized in two main priorities: 1) promote health and wellbeing in WRA; and 2) improve birth outcomes. The PRMCAHP **Preventive Care Guidelines for WRA** (PCGWRA), address chronic conditions, mental and oral health, routine screenings, and prenatal care recommendations, among others. The guidelines will be distributed and continuously updated as needed. A WRA Preventive Care Log will be created and disseminated among GHP WRA and pregnant women to foster preventive health. The Title V Home Visiting Program (HVP), Prenatal Care Courses, and Community Outreach and Education will be continued to achieve the priorities set for the next 5 years.

PERINATAL/INFANT HEALTH DOMAIN

In 2019 the number of infants was 21,245 that represents less than 1% of the PR total population (ACS 2018). Among this population, *97.2%* were insured during 2019. Infant mortality (IM) decreased in average 1% from 2014 to 2018 (7/1,000 vs. 6.7/1,000). Preliminary 2019 IM data is 6.5/1,000, remaining similar to the 2018 data.

The 5 identified needs in this domain are:

Causes of Infant Mortality

VS 2018 showed that the first cause of infant mortality was congenital malformations (50% of all deaths) followed by conditions originated during the perinatal period (17%). However, sleep-related Sudden Unexpected Infant Deaths (SUIDs), was among the leading causes of infant deaths between 1 to 12 months of age in 2016 and as the first cause in 2017 and 2018. PRPRAMS reported in 2018 that 43.6% of infants were placed on their backs to sleep and 29.1% are placed on a separate approved sleep surface, while 24.3% are placed to sleep without soft objects or loose bedding. Thus, only 8.7% of were placed to sleep in safe environment (PRPRAMS 2018). From 2014 to 2018, infant mortality related to premature births has decreased in average 0.5%, keeping the rate below 3 deaths for every 1,000 LBs (VS 2018: 2.1/1,000 LB).

Infant Development

About 63% of FCHCs identified infant exposition to electronic devices as a need of infants that affect their development. Title V HVP performs ASQ-3 and ASQ:SE-2 screening tests to participant infants of the program. By 2018, 7.3% out of 1,409 screened infants presented high risk screening scores. All of them were referred to different services

according to their needs. Only 1 refuse referral and 6 did not qualified for referral. About 82% of the infants with high risk screening scores completed the referral, while 12% did not.

Perinatal Death

Perinatal mortality (PM) was 7/1,000 live births in 2018. Since 2014 PM has decreased in average 1%. PPOR analysis from 2015 to 2018 reveals that most excess of deaths occurred during the Maternal Health and Prematurity (0.6/1,000) and Maternal Care (0.4/1,000) periods. Both periods together compose 74% of all fetal and infants' deaths.

Abuse and Neglect

About 56% of FCHCs participants identified that infants are often exposed to abuse and neglect. The PRPRAMS data reported in 2017 that 3.3% of women who had a LB who reported physical abuse during pregnancy, decreasing 21.2% in 2018 (2.6%). According to data of the Family Department, the cases of child abuse and neglect have increase in the last three years (2016: 14.8% to 2018: 43.1%).

Asthma

About 22% of FCHCs respondents identified asthma and allergies as the condition that mostly affects infants. According to the Asthma Burden Report (PRBRFSS 2015-2017), 14.9% of children 0 to 4 y/o reported current asthma, lower than the other age groups, except 15 to 17 y/o (11.9%). On the other hand, 15.5% of children 0 to 4 y/o reported lifetime asthma, lower than the other age groups and with a significant difference ($p<0.05$) when compared with children 15 to 17 y/o (25.8%).

PR TITLE V AND PERINATAL/INFANT HEALTH: The needs in this domain are summarized in one priority: decrease of infant mortality. The PRMCAH Program **Prenatal Curriculum** – offered by the CHWs and HEs – for pregnant women and their families, promotes the importance of prenatal, natal, and post-natal health care with emphasis on healthy lifestyles, changes during pregnancy, alert signs, delivery plan, breastfeeding, baby care and family planning. Additionally, the media campaign *"Encuentro de mi Vida"* website provides valuable information for all pregnancy periods and infant care. Title V HVP nurses offer participants case management, care coordination, screening for risk factors, support, and education services with a biopsychosocial approach.

CHILD HEALTH DOMAIN

According to the 2019 ACS there were 273,144 children 1 to 9 y/o that represent 8.5% of the total PR population. About 97.4% of the child population were insured during 2018-2019. From 2014 to 2018 the child mortality rate presented variability, dramatically increasing in 2016 (17.1/100,000) and decreasing to 11.2/100,000 in 2018. Preliminary mortality data for 2019 shows an increase to 13.2/100,000. The three leading causes of death among children were: unintentional injuries (20.0%), neoplasms (17.1%) and septicemia 5.7%).

The 5 identified needs in this domain are:

Child Preventive Visits

About 28% of FCHCs participants reported that the prevention practice parents less perform is taking their children to their annual preventive visits. According to PRBRFSS a significant 8% increase ($p<0.05$) was observed in the annual preventive visits between 2017 (79.4%) and 2018 (85.4%). On the other hand, a significant ($p<0.05$) decrease was observed in the oral health preventive visits in children 1 to 11 y/o between 2017 (72.6%) to 2018 (68.4%). Furthermore, the percent of treated teeth with caries has significantly ($p<0.05$) increased between 2015 (7.2%) to 2018 (15.7%) in the same age group.

Mental Health

According to PRBRFSS, the percent of children 1 to 11 y/o diagnosed with depression, anxiety or behavioral problems has decreased from 2016 (18.9%) to 2017 (15%), while the percent of children with these mental health conditions receiving treatment increased during this period (84.3% to 90.1%).

Child Obesity

About 41% of FCHCs respondents identified that parents do not limit the time spent on electronic devices to their children 1 to 9 y/o. Currently there is no data in PR about children's exposition to electronic devices. However, according to PR WIC, the percent of participating children 2 to 5 y/o with a BMI ≥ 85 has significantly increased ($p<0.05$) during the last three years (2016: 16.2% vs 2018: 18.6%). On the other hand, PRBRFSS reported that about 89% (2017) of children 1 to 11 y/o are physically active for at least 60 minutes a day, an increase of 3.6% since 2016 (85.2%).

Immunization

Despite the increase in preventive medical visits, data from the PR Immunization Registry (PRIR) show that the immunization rate has been decreasing in children 6 to 10 y/o for all mandatory vaccines since 2014. The fact that there are few pediatricians who vaccinate children may force parents to seek alternate ways to receive this service.

Asthma

About 44% of FCHCs respondents identified asthma and allergies as a need that affects children 1 to 9 y/o. Comparing between age groups, children 5 to 9 y/o, reported more frequently current asthma (16.9%) and lifetime asthma (24.6%) than children 0 to 4 y/o (14.9% and 18.5%, respectively). However, compare to older age groups, lifetime asthma is more prevalent in children 10 to 14 y/o (33.2%) and 15 to 17 (25.8%). No deaths were reported for asthma in children 1 to 9 y/o (VS 2018).

PR TITLE V AND CHILD HEALTH: All needs in children will be addressed by the priority for this domain: improve preventive health in children. Children's health promotion includes two parenting courses targeted at parents of 0-5 years and 6-11 years, respectively. The courses center on the physical, mental, and emotional health and wellbeing of infants and children, and include healthy eating, physical activity, preventive/routine medical visits, personal safety, home safety, growth/developmental stages, and positive parenting. The

PRMCAHP also developed and constantly updates the **Pediatric Preventive Health Care Guidelines (PPHCG)** which is disseminated to the public, academia, health professionals and health insurance companies.

ADOLESCENT HEALTH DOMAIN

According to the ACS, in 2018 the number of adolescents 10 to 21 y/o was 483,016 that represents 15.1% of the total PR population (10-14 y/o: 37.3%; 15-17 y/o: 24.8%; 18-19 y/o: 18.7%; and 20-21 y/o: 19.3%). During 2018, *95.8%* of adolescents10-21 y/o were insured (ACS 2018). Mortality rates in adolescents are significantly ($p<0.05$) decreasing for all age groups (10 to 14 y/o: 28%; 15 to 17 y/o: 18%; and 18 to 19 y/o: 16%). The leading causes of deaths vary according to age groups; however, motor vehicles crashes, homicides, unintentional injuries, and suicides are among the first four causes in all age groups.

The 5 identified needs in this domain are:

Mental Health

About 44% of FCHCs participants identified depression, stress, and anxiety as the health conditions that mostly affects adolescents. According to PRBRFSS, the percent of adolescents 12 to 17 y/o diagnosed with depression, anxiety or behavioral problems has slightly increased from 2016 (17.3%) to 2017 (17.4%), while the percent of children with these mental health conditions receiving treatment decreased by 8% during the same period (88.3% to 81.3%).

Bullying and Cyberbullying

Since bullying and cyberbullying are linked both needs will be addressed as one. About 41% of FCHCs participants identified bullying as the social situation that mostly affects adolescents. According to PRYRBSS, bullying/cyberbullying significantly increased ($p<0.05$) between 2011 and 2017. In 2017, about 17% of 9^{th} to 12^{th} grade students reported being bullied, and this rate is higher in females (20.2%) than in males (13.6%); and 13% reported of being bullied cybernetically, higher in females (17%) than in males (9%). Consequently, 19.6% of students were frequently absent from school for feeling insecure (females: 21.1% vs. males: 17.9%).

Alcohol Use

Thirty six percent (36%) of FCHCs respondents identified the use and abuse of alcohol as a habit that is affecting adolescents. According to the PRYRBSS (2011-2017) alcohol consumption is significantly increasing ($p<0.05$) in 9^{th} to 12^{th} grade students, even when stratified by gender. In 2017 more than half (61%) of the students reported drinking alcohol at some time in their life, higher in females (65.9%) than in males (55.6%). Alcohol consumption during the last month is significantly decreasing ($p<0.05$). At least 24% of the students reported consuming alcohol during the last month (female: 25.6% vs. male: 22.2%).

Chlamydia in Adolescents (10 to 19 Y/O)

Alcohol consumption inhibits the senses and exposes adolescents to risky behaviors. For the HNA Advisory Committee chlamydia is an outcome of a risky behavior among adolescents. For the last 5 years, chlamydia incidence rates are increasing for the 10 to 14 y/o (2014: 6.3/100,000 vs. 2018: 8.1/100,000), and there is a significant difference ($p<0.05$) when compared by gender (female: 12/100,000 vs. male: 3.9/100,000). The rate in adolescents 15 to 19 y/o are even higher when compared with the 10-14 age group. The incidence of chlamydia has increased by 8% in the last 5 years (2014: 379.9/100,000 vs. 2018: 474.7/100,000). During this period, when compared by gender, there is a significant difference ($p<0.05$) between females (863.4/100,000) and males (102.8/100,000).

PR TITLE V AND ADOLESCENT HEALTH: The needs identified in this domain are summarized in the priority: improve health and wellbeing of adolescent. The **PPHCG** includes adolescent health. The Comprehensive Adolescent Health Program (CAHP) serves adolescents and young people from 10 to 22 years. It seeks to optimize their physical, mental, social, and spiritual development, health, and wellbeing. All actions are guided by the Positive Youth Development Model that views youth as resources capable of assuming responsibilities and contributing to health strategies and policies. The **Youth Health Promoters** (YHPs) and the **Youth Advisory Council** are the two main initiatives of the CAHP.

CHILDREN WITH SPECIAL HEALTH CARE NEEDS DOMAIN

According to the 2019 MCH-JS, the prevalence in PR of CSHCN 0 to 17 years of age is 27.3%. This translates into 162,101 CSHCN. Fifty nine percent (59.07%) are male and almost half (42%) are between the ages of 4 to 10. Most frequent conditions in the CSHCN group are asthma (38.4%), speech disorder (35.6%), anxiety (28.3%), learning disabilities and ADD/ADHD (26% each), behavioral problems (21.9%), headaches (19%), and developmental delay (17.4%). Prevalence of ASD has increased to 3.1% (1 in 33). Congenital defects were the leading cause of infant mortality in PR in 2018 (PR-BDSPD Annual Report, 2017). Seventy two percent (72.1%) of CSHCN are covered by Medicaid, 24% have private insurance and 1.3% are uninsured.

The 5 identified needs in this domain are:

Access to pediatric specialists

Focus groups' participants concurred on the need of pediatric specialists, especially geneticists. Some parents said they have waited up to a year to see a geneticist. Families living outside the metro area reported there is a lack of health specialized services for CSHCN where they live. This may result in hours of traveling, sometimes 2-3 times weekly to receive services. Based on the PR Health Licensing Board, the number of pediatric specialists has decreased by 3.4% from 2010 to 2018, mostly due to migration to the USA. MCH-JS shows that 19.2% of CSHCN families who needed a specialist during the last 12 months could not access one.

Families with ASD children feel there are physicians and other health and non-health ASD care professionals who lack knowledge about ASD and how to manage the condition. They also spoke about the lack of schools and services specialized on ASD after the child

turns three (3) years of age, and about the high costs of the private ones. In fact, service waiting lists in the CSHCN Program Autism Centers increased around 126% during year 2019.

Access to chromosome and genetic labs

For some families with children diagnosed with genetic conditions, accessing a genetic laboratory may be difficult due to the high costs. Key informants reported that most public and private health insurance plans do cover or authorize the laboratories. However, for some laboratory panels the insurance deductibles may be too high for a family to pay. In those cases, the laboratory test may be delayed while the family gets the money. In addition, most of these specialized laboratory tests are done outside PR, which extends the time for the results to arrive. In the 2015 PR-CSHCN Survey, 19% of families with a child in need of a genetic or metabolic laboratory could not access the test. Of these, 66% said they could not access it because of the high costs, and 29% because the insurance plan did not cover the test.

Coordinated and continuous health care

Key informants pointed out that care coordination is part of the service protocol in health centers such as FCHCs, while for solo PCPs or small practices, adequate care coordination may be difficult since it is not covered by health insurance plans. They also pointed out the importance of including health plans when care coordinating. Based on the MCH-JS, 25.1% of families with CSHCN reported they received help to coordinate child's care among different doctors/services. Of the group of CSHCN families that reported the need for care coordination support (10%), 50% reported they usually, and 50% reported they sometimes received the need they wanted. Eighty two percent (82%) referred to be very satisfied with the communication among doctors. Overall, 83.9% of CSHCN families received an effective care coordination. As pointed out in focus groups, families with scarce resources may face more difficulties in finding the needed care. Based on the 2019 MCH-JS, 84.6% of CSHCN families with less than $15,000 annual income received an effective care coordination compared to 100% of CSHCN families with more than $50,000 annual income. This data is statistically significant ($p < 0.000$).

Family-centered care (FCC) and support

Focus groups' participants feel that their CSHCNs are well served in the PR-health care system but not so much the parents or caregivers. They spoke of a wide range of feelings they had when they first were informed about the child's diagnosis: fear, sense of loss, guilt, overall life changes, accepting and adapting to this unexpected situation. The main needs they expressed were the access to information; find the correct place for their child to be treated (a place of reassurance); emotional support; family, social, and/or spiritual support; and health care professional sensitivity. Families also spoke of changes in needs across their life span while taking care of a CSHCN such as psychological and emotional needs, time for themselves, and respite. The 2019 MCH-JS indicated that 86.5% of families with CSHCN received FCC during the past 12 months.

Transition to adult health care

Transition to adult health care is a crucial life event for YSHCN. Some key informants raised the issue that there are physicians who lack knowledge about the conditions of adults with special health care needs. However, YSHCN participants at the conversational meeting reported they are satisfied with their adult health care but miss their pediatricians. Some of them still visit both. Focus groups' families with YSHCN spoke about barriers/difficulties during the transition process involving other aspects of adulthood, such as education and work. Independent living key informants talked about how late many parents go to receive transition to adulthood and independent living support. Frequently, parents realize the need of transition support when they are themselves getting older, and then it may be too late.

According to the 2019 MCH-JS, 6.4% of YSHCN and 17.4% of non-YSHCN received the necessary support for a successful adult health care transition. This might reflect a lack of skills in the YSHCN health field. PR-GIP special coverage ends at 21 years of age. Of the group of families who reported they did not know how the child will be insured after turning 21 (59.7%), only 3.4% reported someone discussed the topic with them.

PR TITLE V AND CSCHN HEALTH: The five prioritized CSHCN domain needs are all elements of the medical home approach: access to care, care coordination, FCC and transition to adult health care. NPM 11 and 12 has been part of the PR State Priorities during the past 10 years. The CSHCN Program will continue to address medical home components at both programmatic and community levels.

CAPACITY NEEDS (CAST-5)

The results of the CAST-5 survey are summarized in the following diagram:

Structural Resources Needs	Data/information Systems Needs	Organizational Relationships Needs	Competencies Needs
• Parts A/B: 28% reported needs in sufficient authority and funding • Part C: 63% in sufficient funding; 37% two-way communication channels with relevant constituencies	• 63% of Parts A/ B and 56% of Part C reported need in access to timely program and population data from relevant public/ private resources • Part C: 63% in adequate data infrastructure	• Parts A/B: 44% reported needs in state and local policymakers • Part C: 41% in state and national entities enhancing analytical and programmatic capacity	• Parts A/B: 28% in experience and expertise in working with and in communities/knowledge and understanding of the state context • Part C: 34% ability to influence the policymaking process

ii. Title V Program Capacity

a. Organizational Structure

The PRDOH is the umbrella agency legally responsible for all public health related matters. The Secretary of Health is appointed by the Governor and confirmed by the Legislature. The agency is organized in two main structural levels: 1) Advisers and Support Units and 2) Operational units and Implementation of Public Policy. The Assistant Secretariat for Family Health and Integrated Services is included in the second level, under which are the Maternal, Child and Adolescent Health Division (MCAHD) that houses the MCHAP (Component A & B) and the Children with Special Medical Needs Division (CSMND) that houses the CSHCNP (Component C). Each Division is organized into two sections:

MCAHD: 1) ***Evaluation, Monitoring, Research and System Development Section*** that houses the PR State Systems Development Initiative and; 2) ***Perinatal, Child and Adolescent Services Section*** composed of these programs: Title V Home Visiting Program; Maternal, Infant and Early Childhood Home Visiting Program (MIECHVP), Partnership for Optimize Family Support for Families of Children Affected by Zika; Early Intervention Services System Part C IDEA; Comprehensive Adolescent Health Services; Personal Responsibility Education Program (PREP); Sexual Risk Avoidance Education Program (SRAE); and Pregnancy Risk Assessment Monitoring System (PRPRAMS).

CSMND: 1) ***Birth Defects and Developmental Disabilities Surveillance and Prevention Section*** which comprises the following: Birth Defect Surveillance and Prevention System (PR-BDSPS), Universal Newborn Hearing Screening Program (PR-UNHSP), Hereditary Disease Detection, Diagnosis and Treatment Program (HDDDTP), Autism Registry, Emergent Threats to Mothers and Babies Surveillance System, Pulse Oximetry Screening for Critical Congenital Heart Defects, Zika Maternal and Child Health Service Program (PR-ZMCHSP), CMS Zika Health Care Services Program, and the Technology Dependent Children and Youth Registry and; 2) ***Children with Special Health Care Needs Program*** **Section *(CSHCN Program)*** which consists of seven (7) Pediatric Centers located in each PR health region and two Autism Centers.

For the Organizational Chart see Attachment: Puerto Rico 2020 Health Needs Assessment Supporting Document

b. Agency Capacity

Several core programs facilitate and complement the health services in PR health care system primary level.

The Home Visiting Program (HVP), staffed by Home Visiting Nurses (HVNs), serves pregnant women and their children up to 24 months after delivery in 71 municipalities. The HVNs do screenings for maternal depression, intimate partner violence, substance use, child development and oral health. They also make referrals to appropriate services as needed and offer health education on maternal and infant/child health topics. A Mental Health Consultant (PHD in Psychology) provides training and support to the HVNs to effectively manage participants' emotional health.

The Community Outreach Program (COP) is staffed by 31 Community Health Workers (CHWs) that provide community health education. The also offer the following courses: a) Prenatal Course that provides pregnant women with tools to maintain a healthy pregnancy and prevent risk factors; b) Parenting Courses targeted at parents of children 0-5 y/o and parents of children aged 6-11y/o on healthy eating, physical activity, preventive medical visits, personal safety, home safety and positive childrearing.

Health Promotion is overseen by the Health Educators (HEs) – one in each Region – responsible for offering community education, parenting courses, and technical assistance to the COP. A key component are media/internet campaigns, dissemination of educational materials and tools, and training and information to health professionals.

The Perinatal Services are provided by the Perinatal Nurses (PNs) that visit birthing hospitals to offer pregnancy and breastfeeding support and post-partum and infant health education. They also promote the Title V HVP and the Prenatal and Responsible Parenting Courses among women.

The Comprehensive Adolescent Health Program (CAHP) promotes adolescence health and wellbeing. The CAHP is staffed by an Associate Director and Healthy Youth Development System Coordinator (HYDS-C), Youth Health Promoter Center Coordinator (YHPC-C) and 6 Regional Coordinators (CAHP-C).The CAHP-Cs coordinate the Youth Health Promoters Project (YHPP) composed of voluntary students that promote healthy lifestyles among their peers in participating schools. The Youth Advisory Council (YAC), led by the HYDS-C, is composed of adolescents that help the DOH identify and implement strategies to improve youth health and wellbeing.

Pediatric and Autism Centers: offer primary level services like screening, pediatric medical evaluation, and referrals to eligible CSHCN 0 to 21 years of age. Service coordinators, social workers and graduate nurses offer enabling services - support and coordination - to CSHCN/families, helping them navigate the system and access care. Allied health professionals offer habilitative services. The staff also inform families and facilitate access to services in the community. While the centers do not qualify to be a medical home (they are not PHCC), they do strengthen the medical home community by connecting with CSHCN's PCPs, making referrals, and supporting families in decision-making. This support fills gaps within the PR health care system as it grows to the medical home approach. Blind and individuals with disabilities who are residents of Puerto Rico are not eligible for receiving Supplemental Security Income under Title XVI.

c. MCH Workforce Capacity

The MCAH Program Components A&B is formed by a multidisciplinary team of professionals housed in the Central Level and 7 Regional Offices. As of June 30, 2020, the workforce consists of 166 regular/transitory employees and 14 (professional services contracts. Of the regular employees 132 (132 FTE) are distributed in the 7 Regional Offices. Among them are 82 Home Visiting Nurses, 31 Community Health Workers, 7 Perinatal Nurses, 6 Adolescent Coordinators and 6 Health Educators across the Island. Among these personnel, there are 7 full-time employees that once were participants of MCAH led programs (HVP and YHPP) or collaborator at the regional level: 4 Home Visiting Nurses, 2 Community Health Worker and one Regional Coordinator. Most Regional teams have a Regional MCAH Director, Coordinator of Maternal and Infant

Health Services, Coordinator of Adolescent Health Services, Health Educator, administrative and support staff.

At the Central Level, there are 9 regular (8.96 FTE) positions that include the MCAHD/MCAHP Director, Manuel Vargas, MD, MPH, an OBGyn with more than 30 years of experience. Thirteen (10.80 FTE) Professional Services Contracts of high skilled health professionals: one Biostatistician, two Epidemiologists, one Evaluator; one Cultural Anthropologist; and three Physicians (Comprehensive Adolescent Health Program Director, Pediatric Consultant, and OB/Gyn Consultant). Other highly skilled contract positions are: one Health Education Component Coordinator; one Healthy Youth Development System Coordinator; one Young Health Promoter Center Coordinator; one Title V Home Visiting Coordinator; one Title Home Visiting Evaluator; and one Consultant in Psychology.

Component C (CSHCNP) consist of a multidisciplinary team of professionals who provide services consistent with the three levels of the MCH pyramid. As June 15, 2020, Central Level holds 10 regular (10 FTE) and one temporary position (1 FTE). Senior level management includes the CSMND/CSHCNP Director, Miguel Valencia-Prado, MD, FAAP, a pediatrician with a developmental pediatrics fellowship, expert in the field of CSHCN, and who has worked for the DOH for 34 years; and the Auxiliary Director, Angela M. Adams, expert in the DOH administrative arena. There are 15 professional service contracts (14 FTE): 2 Consultants compromised with the re-enforcement of the 220 BIDA Law for the Well-being, Integration and Development of People with Autism, a Family Representative, an Evaluation Specialist, a Biostatistics Specialist, 2 Care Coordinators and 2 Data Specialists. Title V funds also supports the PR-BDSPS and the PR-UNSHP with two Social Workers for each program, and with a Maternal Fetal Sonographer Liaison who timely collects NTDs affected pregnancies ultrasound test results.

At the Regional Level, staff consist of 55 FTE regular/temporary positions, and 51.6 FTE contractual positions. The table below shows the total of FTE, and number of contracts/regular positions: pediatricians (Ped), nurses (RN/LPN), physical therapists and assistants (PT/PTA), occupational therapists and assistants (OT/OTA), speech and language pathologists and speech therapists (SLP/ST), social workers (SW), service coordinators (SC), nutritionists (Nt) and Clinical Psychologists (LCP). Other staff (administrative, data, informatics) are under the “Other” column.

Center	FTE	Regular/ transient	Contract	Ped	RN/ LPN	PT/ PTA	OT/ OTA	SLP/ ST	SW	SC	Nt	LCP	Other
Arecibo	11.6	9	3	1	3	0	1	2	1	1	0	0	3
Bayamon	9.7	2	8	1	1	0	1	2	1	1	0	1	2
Caguas	9.7	4	7	1	1	1	1	1	0	1	1	2	2
Fajardo	3	1	2	1	0	0	0	0	1	0	0	0	1
Mayaguez	10	8	3	1	2	2	0	2	0**	0	0	1	3
Metro	28.3	18	11	1	6	4	4	4	2	1	1	2	4
Ponce	20	13	8	0	2	3	3	2	1	0	0	1	9 *
Metro AC	7.5	0	8	1	0	0	1	1	1	1	0	3	0
Ponce AC	6.8	0	7	0	0	0	1	1	1	1	0	2	1
Total	106.6	55	57	7	15	10	13	13	6	5	3	10	27

* This includes a dentist and a dental assistant ** Social Worker available through state funds.

In addition, the following staff provides services on a fee for service bases at the RPCs: 2 Audiologists (Metro and Ponce PCs); a Pediatric Surgeon in Metro; and a Pediatric Orthopedic in Mayaguez. Through an agreement with the Medical Science Campus, UPR, CSHCN receive the following services at the Metro PC: orthodontics, ophthalmology, neurosurgery, and orthopedics.

iii. Title V Program Partnerships, Collaboration, and Coordination

Other MCHB investment: Within the MCAH structure, there are other MCHB programs that share the MCAH Director as their Project Director and receive support from administrative and support MCAH staff (accountant, purchasing agent, secretaries). The SSDI program is responsible for data collection, analysis, and linkages. The MIECHV program addresses WRA and pregnant women's health, infant and child health.

Other Federal investment: The WIC program fosters healthy nutrition in pregnant women, infants, and children and collaborates with the identification of children with positive hearing screening but with no diagnostic tests results. FEMA collaborates with the natural disaster preparedness of families with technology-dependent children. The Immunization Program addresses vaccines as a protective factor. Four grants housed in the MCAH also support our efforts: the *Early Intervention Program* offers services to children with developmental delays; the *Sexual Risk Avoidance Education* and the *Personal Responsibility Education* programs address adolescent health; the CDC PRAMS collects state-specific, population-based data on maternal attitudes and experiences before, during, and after pregnancy. MCAH also collaborates with the CDC HIV/STDs Prevention Division in community mobilization and the day to get tested for HIV/STDs. The Centers for Medicare and Medicaid Services provides data of EPSDT services for the Title V Annual Report and sponsors the CMS ZHCSP at the CSMND.

Other HRSA programs: The HRSA-funded Health Centers were the sites for the MCAH HNA survey carried out among their clients and providers and facilitated access to key informants for the CSHCN qualitative data collection. They also facilitated access to key persons for the CSCHN qualitative study. The Ryan White HIV/AIDS Program administratively housed at the DOH Central Office for the Management of AIDS and STD provides all services to low income HIV positive or AIDS patients. HRSA has supported PR during the Zika Outbreak through the PR-ZMCHSP.

State and local MCH programs: The MCAH Program has seven regional offices that implement the strategic plan; give feedback and report accomplishments and barriers to make needed revisions in achieving program goals. The CSHCN Program provides comprehensive, quality, and family-centered services and support to CSHCN and their families through the seven RPCs and two Autism Centers.

Other programs within the State Department of Health: MCAH share resources, trainings and data with the Chronic Disease and Health Prevention Programs of the Auxiliary Secretariat for Health Promotion. The Administration of Mental Health and Anti-Addiction Services (ASSMCA) offers trainings and shares mental health data. The Office of Informatics and Advanced Technology (OITA) links Medicaid participants with live births data and gives support to the Autism Registry and PR-EHDI-IS. The Demographic

Registry Office has team up with MCAHD to conduct PRAMS, in addition to data access. It also hands out the developmental guide "*Passport to Health"* to families registering their newborn. The Medicaid Program participates in the MCAHP Regional Boards and accepts MCAH referrals of identified uninsured women, children, and adolescents. The Office of Regulation and Certification of Health Professionals provides requested data for the CSMND. The MCAHP shares data with the Emergency Medical Services for Children for the prevention of unintentional injuries that form part of the HNA Advisory Committee. The MCAHP also works in collaboration with the Office of Public Health Preparedness and Response and is part of the Behavioral and Mental Health Expert Committee.

Other governmental agencies:

a. Insurance Commissioner Office and PR Health Insurance Administration: provide data on health services for the MCA/CSHCN population
b. Education Department: MCAHP provides resources and cross coordination of health promotion actions in public schools. The DE collaborates with the implementation of the protocols for ASD early identification and diagnosis, and with the identification of technology dependent children.
c. Family Department: Has representation in MCAHP Regional Boards as well as providing data for Title V Annual Report. MCAHP also is a member of the Children Justice Act Committee aimed at improving the policies for the evaluation and management of child abuse. Through its Child Care Program, it collaborates with DD and ASD early identification.
d. Head Start and Early Head Start Programs: Participate in MCAHP Regional Boards in addition to providing data. MCAHP offers these programs resources and education to their staff and parents.
e. PR Institute of Statistics: Makes MCAHP reports and research findings available for the public through their website. The Institute also supports MCAH/CSHCN Programs by providing needed data for the HNA and Title V Annual Report.

Tribes, Tribal Organizations and Urban Indian Organizations: PR has no tribes, Tribal Organizations, and/or Urban Indian Organizations.

Public health and health professional educational programs and universities:

a. UPR University – Agricultural Extension: Collaborate with CAHP and are part of the MCAHP Regional Boards and the HNA Advisory Committee.
b. Health and Justice Center, San Juan Bautista School of Medicine: Provides training to Title V Home Visiting nurses.
c. Institute on Developmental Disabilities, UPR Medical Science Campus: Collaborates in the revision of the Pediatric Care Guidelines and provides training to Title V Home Visiting nurses.
d. PR Family to Family Health Information Center: collaborates with the CSHCNP giving information to NICU families and promoting the CSHCNP.
e. Medical Science Campus, University of PR – collaborates with CSHCN access to pediatric specialists
f. PR-Neonatal Screening Laboratory: PR- HDDDTP collaborates offering service coordination for infants with positive test results.

Other state and local public and private organizations that serve the state's MCH population:

a. United Way: Sponsors the 211 line and supports MACH health promotion activities.
b. March of Dimes: Sponsors the Programmatic Committee in which MACH participates.
c. Hospital Association: Supports MCAH surveillances, research, and policy implementation in hospitals.
d. AAP Puerto Rico Chapter, PR Pediatric Society: child/adolescent health promotion.
e. Association of Primary Health Care of PR: Supports MCAH HNA and programmatic efforts and facilitates access to HRSA Funded Community Health Centers.
f. Highway Safety Commission: provides MCAHP with data related to injury prevention.
g. Oral Health Alliance: MCAHP is a member of the alliance.
h. La Leche League PR, Proyecto Lacta, PR Breastfeeding Coalition, Promani, ASI, Quality Office of La Fortaleza, Women and Patient Procurator: Participate in the MCAHP sponsored Breastfeeding Alliance.
i. Institute for Youth Development: Shares data of adolescent health to CAHP.
j. PR Boys and Girls Club: YAC collaborates in assisting them to develop a model for their advisory council.
k. Pro Familia (Planned Parenthood): Collaboration with CAHP in the development of the adolescent friendly services.
l. PR-ACOG: Is part of the HNA Advisory council. PRMCAH Program shares data that is needed for the creation of new programs and/or services for WRA and pregnant women.
m. PR Society of Pediatric Dentistry: Collaborates with MCAH Program in all oral health initiatives.
n. Proyecto Nacer: Collaborates with CAHP in the development of the adolescent's friendly services.
o. Maternal Fetal Medicine Specialist: Collaborate with LOCATe and the development of the PR Perinatal Care Guideline.
p. APNI: collaborates with the CSMND through health and services promotion, research, and studies' support, and with the enhancement of family engagement.
q. SER de PR: facilitates access with YSHCN to collect their inputs on transition guides and educative material.
r. MAVI: collaborates with YSHCN studies and surveys.
s. Office of Advocacy for People with Disabilities collaborates with studies and surveys.
t. PR-PKU Association: PR-HDDDTP participates in this association

c. Identifying Priority Needs and Linking to Performance Measures

The process for the identification of priority needs involved 3 steps:

Step 1. Discussion of findings by domain and current NPMs and NOMs with the HNA Advisory Committee. Based on the findings, a total of 83 potential needs (23 WRA, 17 perinatal/infant, 10 child, 21 adolescents, and 12 CSHCN) were identified.

Step 2. Prioritization of potential needs by members of the HNA Advisory Committee (39 participants). Members were divided into each of the 5 Title V domains according to their expertise and population served or represented. Each Domain Group (DG) prioritized the potential needs based on the following criteria: 1) magnitude of the problem; 2) severity of the consequences; 3) socioeconomic impact; and 4) PR Title V human and economic resources (adapted from CDC's Prioritizing Public Health Problems 2013). Weights were assigned to each criterion. Each DG identified 5 needs and selected by consensus 3 possible strategies/activities that should be considered in addressing the needs. All together a total of 25 potential needs were identified.

Step 3. Based on the input of the HNA Advisory Committee, the HNA Steering Committee analyzed Title V resources allocation, data availability, other agencies efforts, and type of interventions and/or strategies for each domain. The CSHCN Advisory Board did the same for the CSHCN Program including evidence-based practices to address the identified needs.

PR Title V listed 9 Priority Needs for the next 5 years. Most priorities from the previous 5YR Action Plan remain the same while some were replaced or revised based on the priority main objective, resources, and capabilities. The 5YR Action Plan centers on the following priorities:

1. **Promote health and wellbeing in women of reproductive age (WRA):** This priority revises priority No.1 from the previous 5YR Action Plan. Unhealthy lifestyles that increase the likelihood of developing chronic conditions, and mental health problems affect women's health whether they plan to have a baby or not. These issues can be addressed by the preventive medical visit that helps women take control over their health, increments the probability of receiving treatment or follow-up care as needed, and reduces the likelihood of adverse birth outcomes, maternal and infant mortality. The percent of women with a past year preventive medical visit is a good indicator to measure WRA health and wellbeing (NPM 1).

2. **Improve birth outcomes:** This priority continues from the previous 5 YR Action Plan and includes preterm births and other conditions and procedures that may affect children's health and survival. Early prenatal care to reduce health conditions developed during pregnancy, oral health of pregnant woman and nutrition evaluation help improve birth outcomes. The percent of women who had a preventive dental visit during pregnancy (NPM 13.1) was selected as the measure to improve birth outcomes.

3. **Decrease infant mortality:** This priority continues from the previous 5 YR Action Plan. Prematurity and LBW infants are among the first causes of infant mortality in PR. Yet, sleep-related Sudden Unexpected Infant Deaths (SUIDs) was one of the leading causes of infant deaths age 1 to 12 months in 2016 and as the first cause in 2017 and 2018. A safe sleeping environment may well contribute to infant mortality reduction. Other contributors are breastfeeding promotion, baby-friendly hospitals, high risk babies born in appropriate hospitals and Hard Stop Policy implementation. The percent of infants placed on their backs, on a separate approved sleep surface without soft objects or loose bedding (NPM 5) was selected as the measure that could reduce infant mortality.

4. **Improve preventive health in children:** This priority replaces priority No. 4 from the previous 5YR Action Plan. Preventive child healthcare that includes the promotion of the Pediatric Preventive Health Care Guidelines (PPHCG) and oral health will enhance children's health and wellbeing. Other issues considered in this priority are unintentional injuries, children's socioemotional development, immunizations, obesity and physical activity, abuse and neglect in children, mental health, and behavioral problems. The percent of children, ages 1 through 17, who had a preventive dental visit in the past year (NPM 13.2) was selected as the measure to follow up preventive health in children.

5. **Improve health and wellbeing of adolescents:** This priority continues from the previous 5YR Action Plan. Healthy lifestyles and preventive visits that focus on adolescent physical, behavioral, and sexual needs can help them be responsible, lead a healthier life, and prevent diseases. Adolescence bullying experiences are related to certain behavioral, emotional, and physical adjustment problems. These are: depression, anxiety, low self-esteem, and isolation; poor school performance; and suicidal ideation and attempts. The percent of adolescents aged 12 to 17 years with a preventive medical visit in the past year (NPM 10) can improve adolescent health and wellbeing. The percent of adolescents, 12- 17 years who are bullied (NPM 9) will also be used to monitor their health and wellbeing.

6. **Medical home for children and youth with special health care needs**: This priority continues from the previous 5YR Action Plan. CYSHCN require care beyond that of typical children and youth. The medical home (patient/family centered, comprehensive, coordinated, and accessible healthcare) is an effective model to meet their needs. The 2019 MCH-JS showed that 57% of CYSHCN and 55.2% of typical children ages 1-17 received health care within a medical home. This percent still needs to improve.

7. **Transition to adult health care for youth with special health care needs:** This priority continues from the previous 5YR Action Plan. Medical advances have extended the life expectancy of CYSHCN and the transition to adult health care is a crucial life event. Yet, there are still many issues that may hinder a successful transition. The 2019 MCH-JS showed that only 6.4% of YSHCN, and 17.4% of non-YSHCN 14 to 17 years of age had a successful health care transition. Efforts to improve this performance measure will continue.

8. **Early screening, diagnosis, and treatment for children with Autism Spectrum Disorders (ASD):** This priority continues from the previous 5YR Action Plan. Growing evidence points to the importance of early screening, diagnose, and treatment for ASD children. Evidence-based intervention can significantly improve the development and quality of life of ASD children. The 2019 MCH-JS showed that 11.2% of children with ASD, 3 to 17 years of age, were identified or diagnosed before three years of age. Efforts must continue to improve ASD early identification.

9. **Prevalence of neural tube defects (NTD) at birth:** This priority continues from the previous 5YR Action Plan. NTD prevalence has decreased in PR from 10.4 in 2014 to 5.6 (provisional) in 2018. However, Healthy People 2020 targets are 3.08 for spina bifida and 2.2 for anencephaly. Efforts will continue to reduce NTD birth prevalence.

Puerto Rico 2020 Health Needs Assessment Supporting Document

Figure 1: Municipalities with a participating HRSA FCHC, Health Needs Assessment 2020

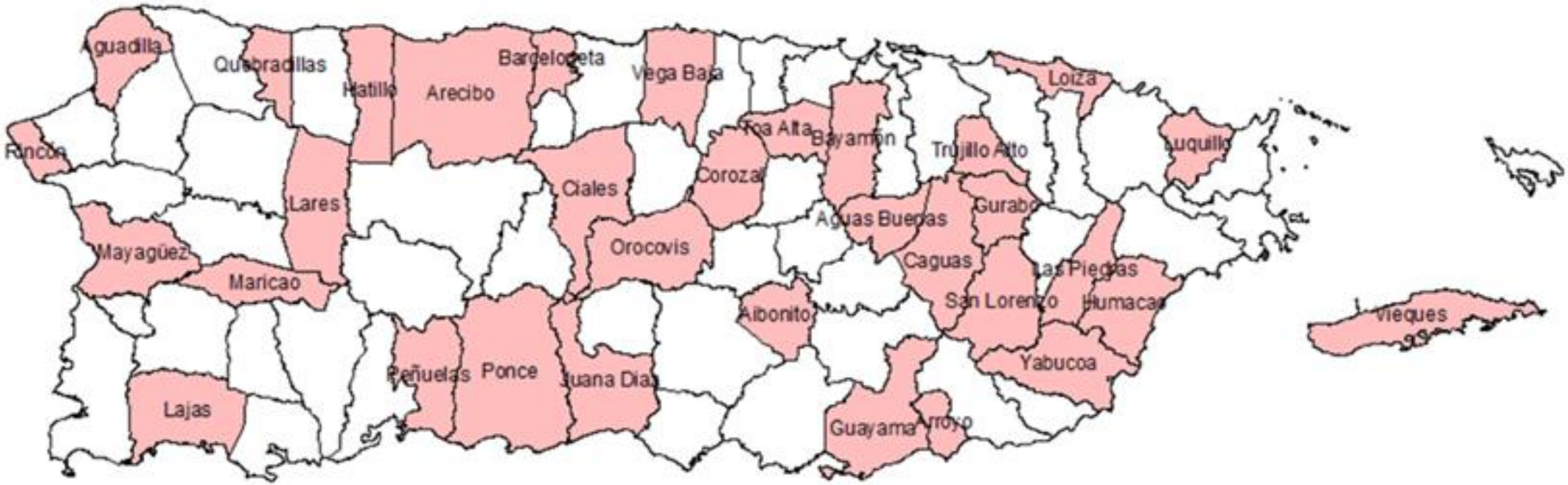
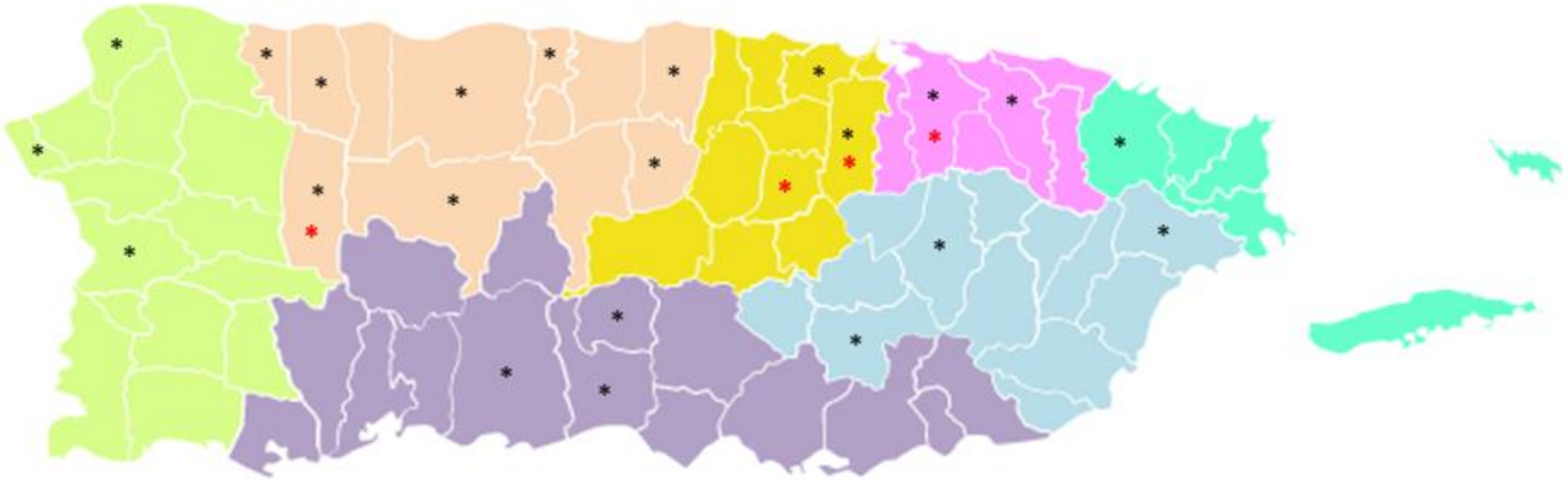


Figure 2: Municipalities were focus groups' families live and were semi-structural interview were carried out, Health Needs Assessment 2020

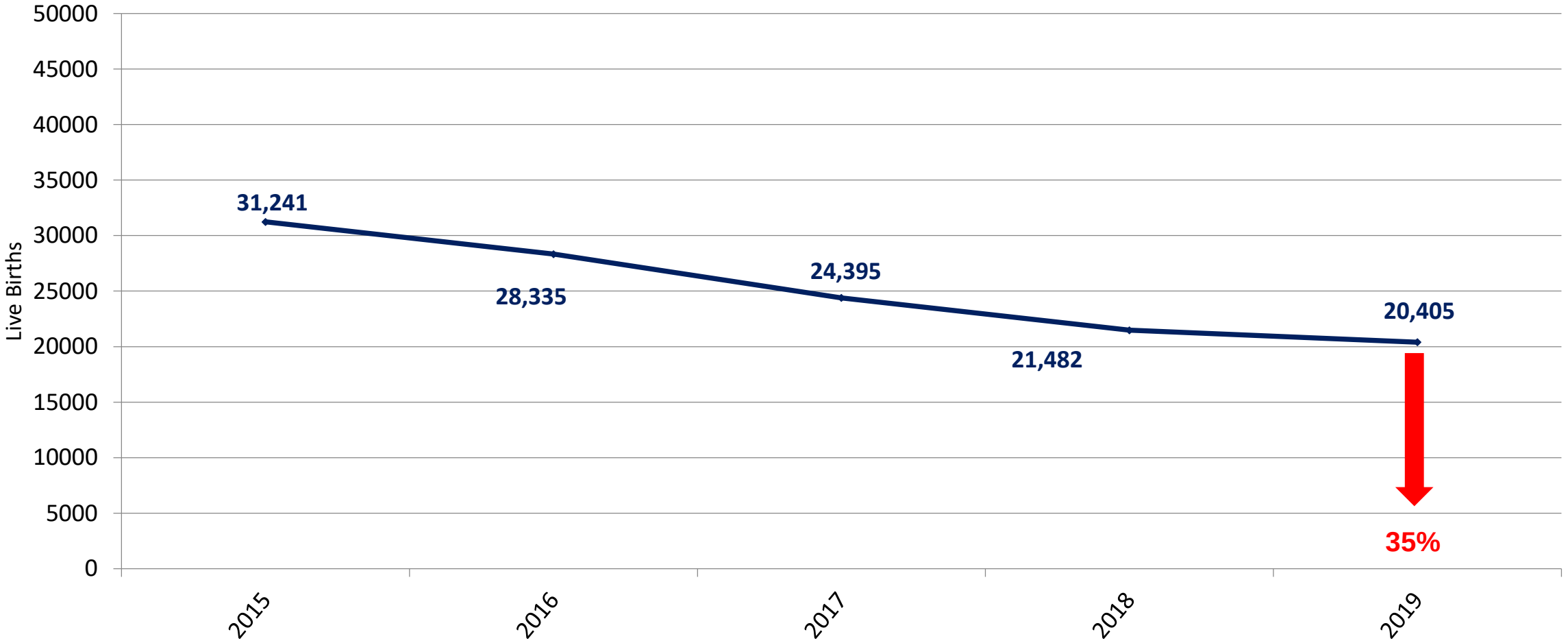


* Focus groups families residence

*Semi-structural interviews with key persons were carried out

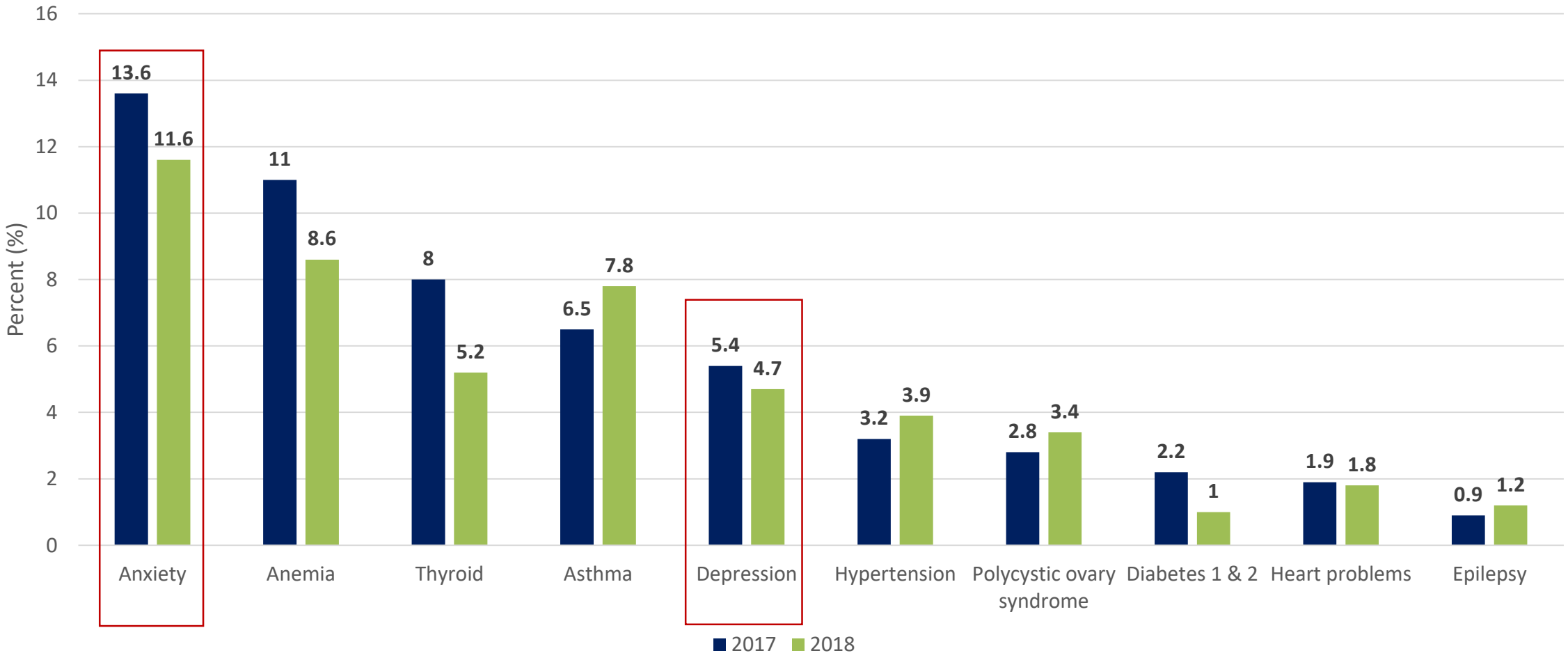
Women/Maternal Health

Figure 3: Live Births: Puerto Rico 2015 to 2019



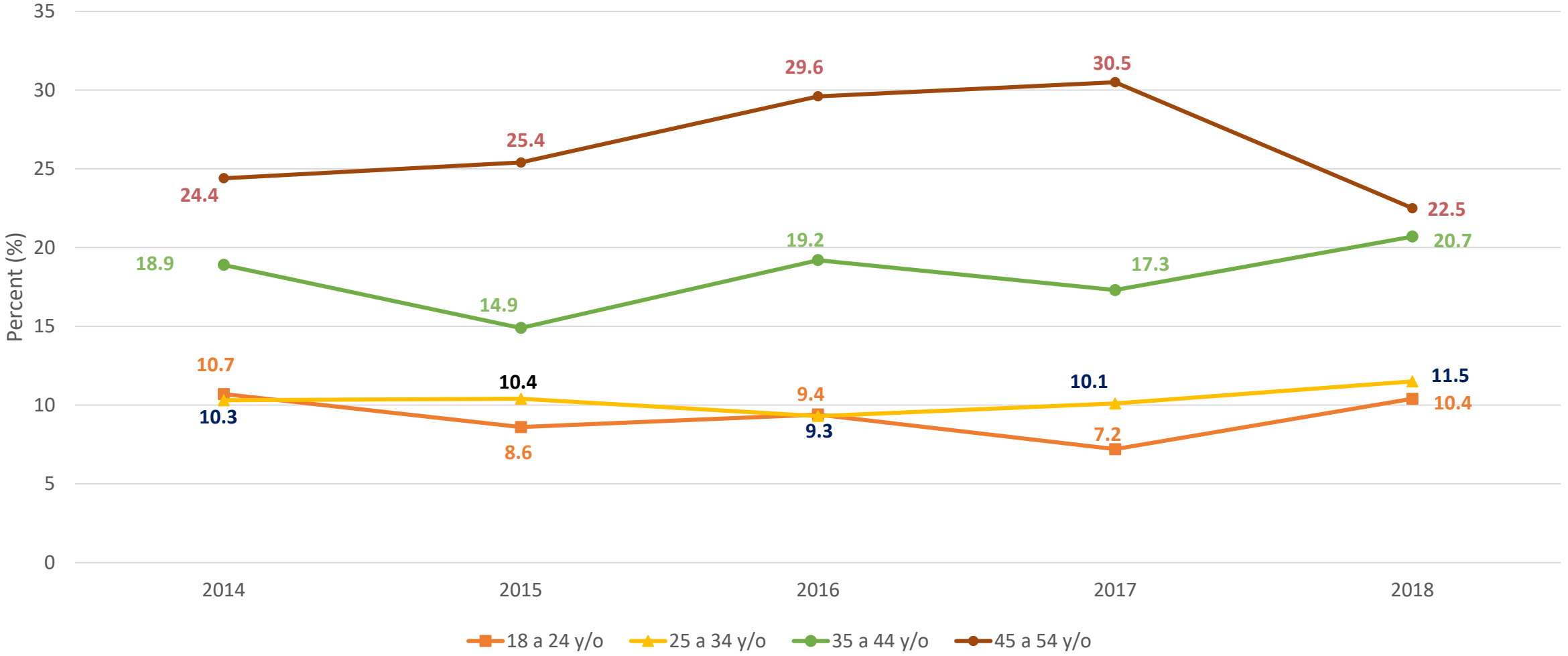
Source: Birth Certificate 2015 to 2019. Demographic Registry and Vital Statistics. PR Department of Health.

Figure 4: Health Conditions 3 Months Before Pregnancy Puerto Rico: 2017 & 2018



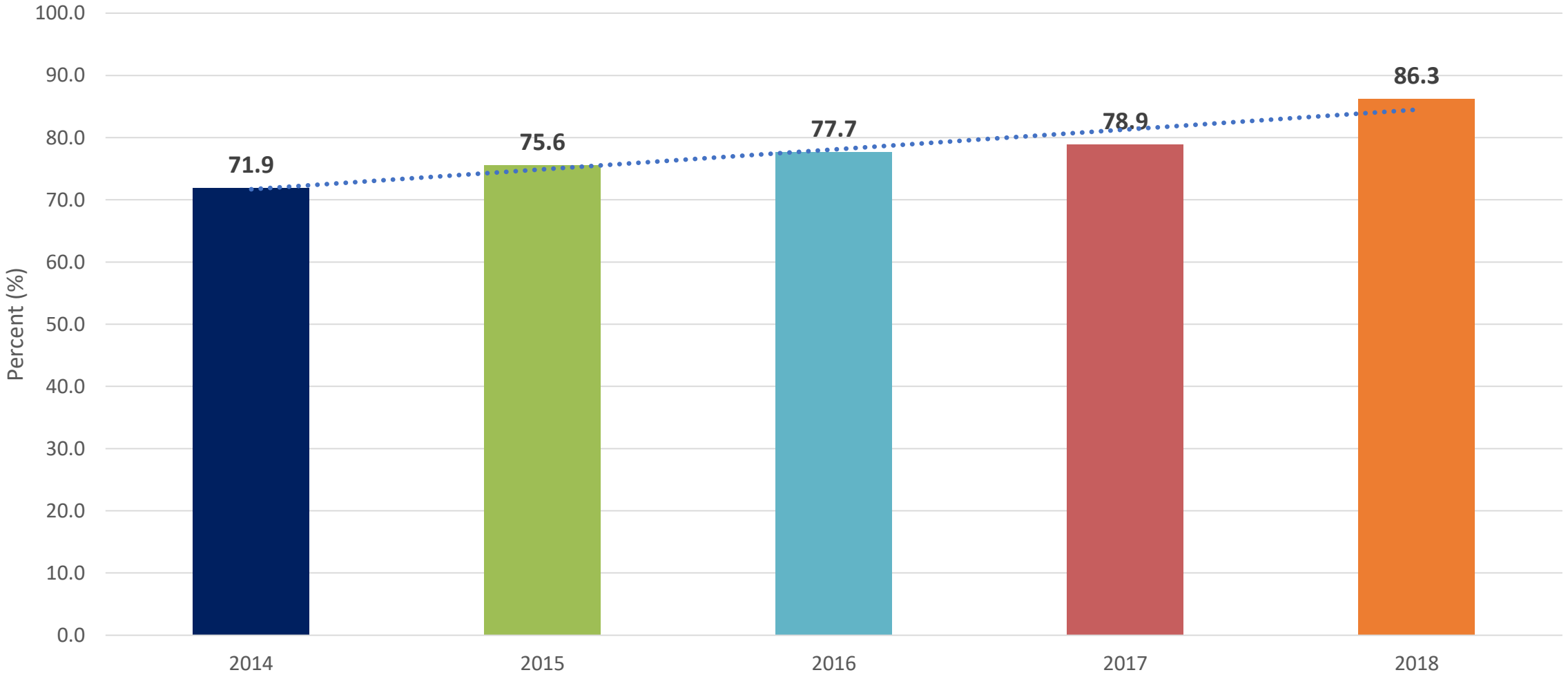
Source: PR-PRAMS 2017 & 2018; PR Department of Health.

Figure 5: Women, by age group, ever told to have a depressive disorder, including depression, major depression, dysthymia, or minor depression
Puerto Rico: 2014 to 2018



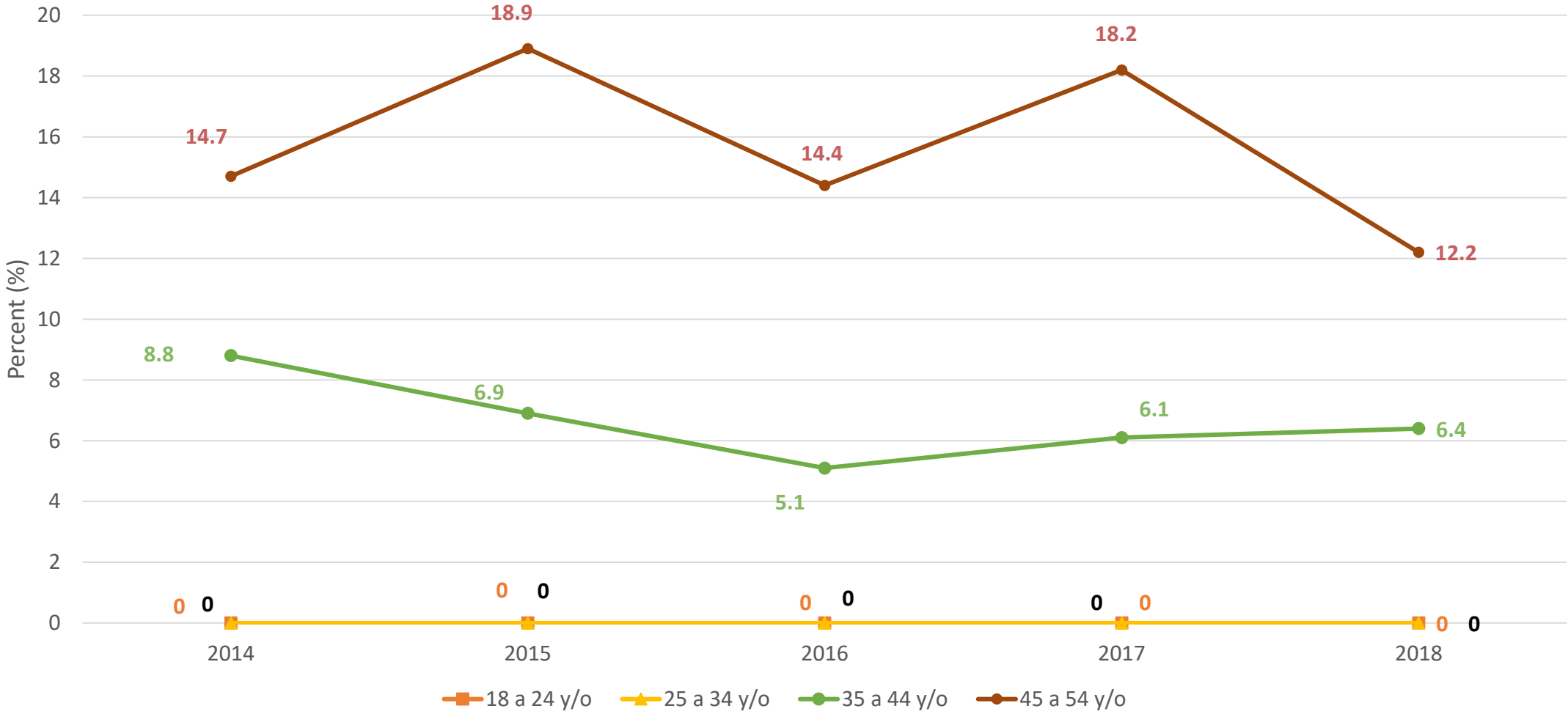
Source: PR-BRFSS, 2014 to 2018; PR Department of Health.

Figure 6: Annual Preventive visits in women 18 to 44 years Puerto Rico: 2014 to 2018



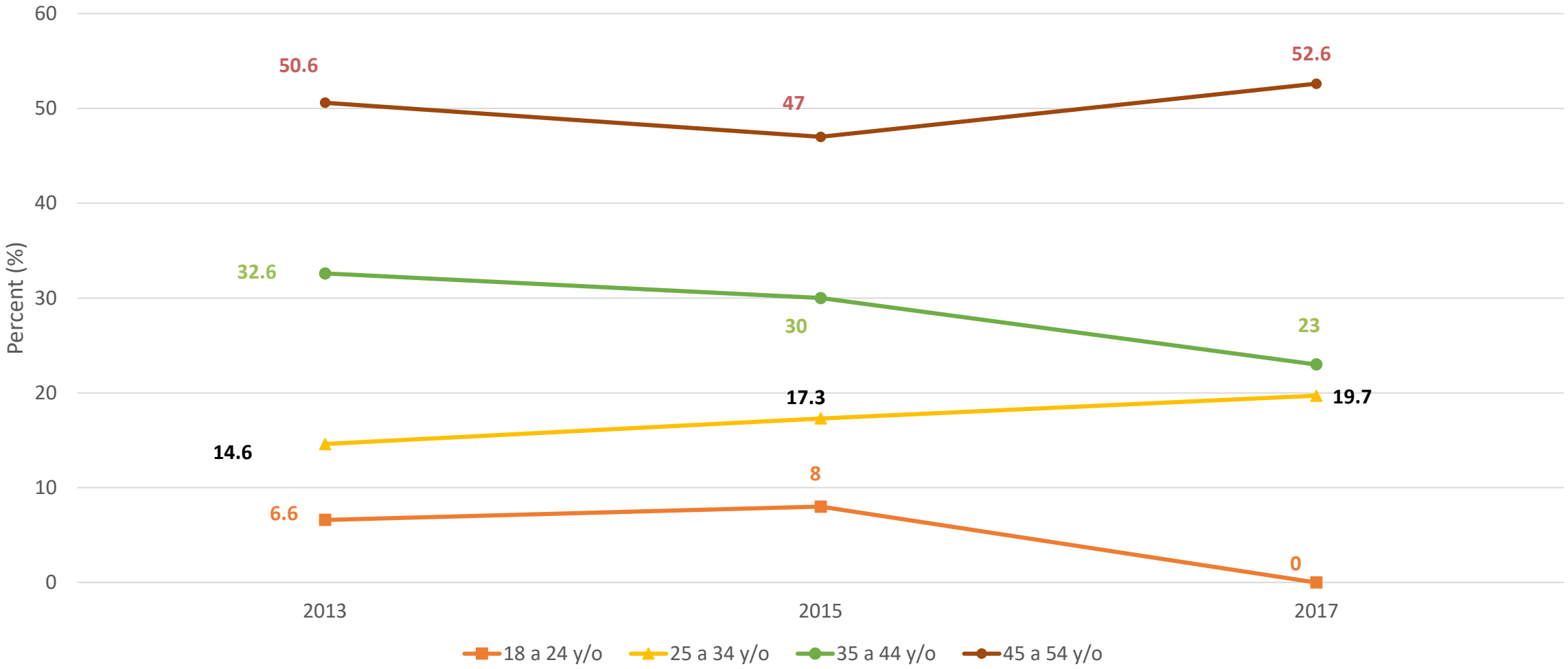
Source: PR-BRFSS, 2014 to 2018; PR Department of Health.

Figure 7: Women, by age group, ever told to have diabetes (excluding pregnancy) Puerto Rico: 2014 to 2018



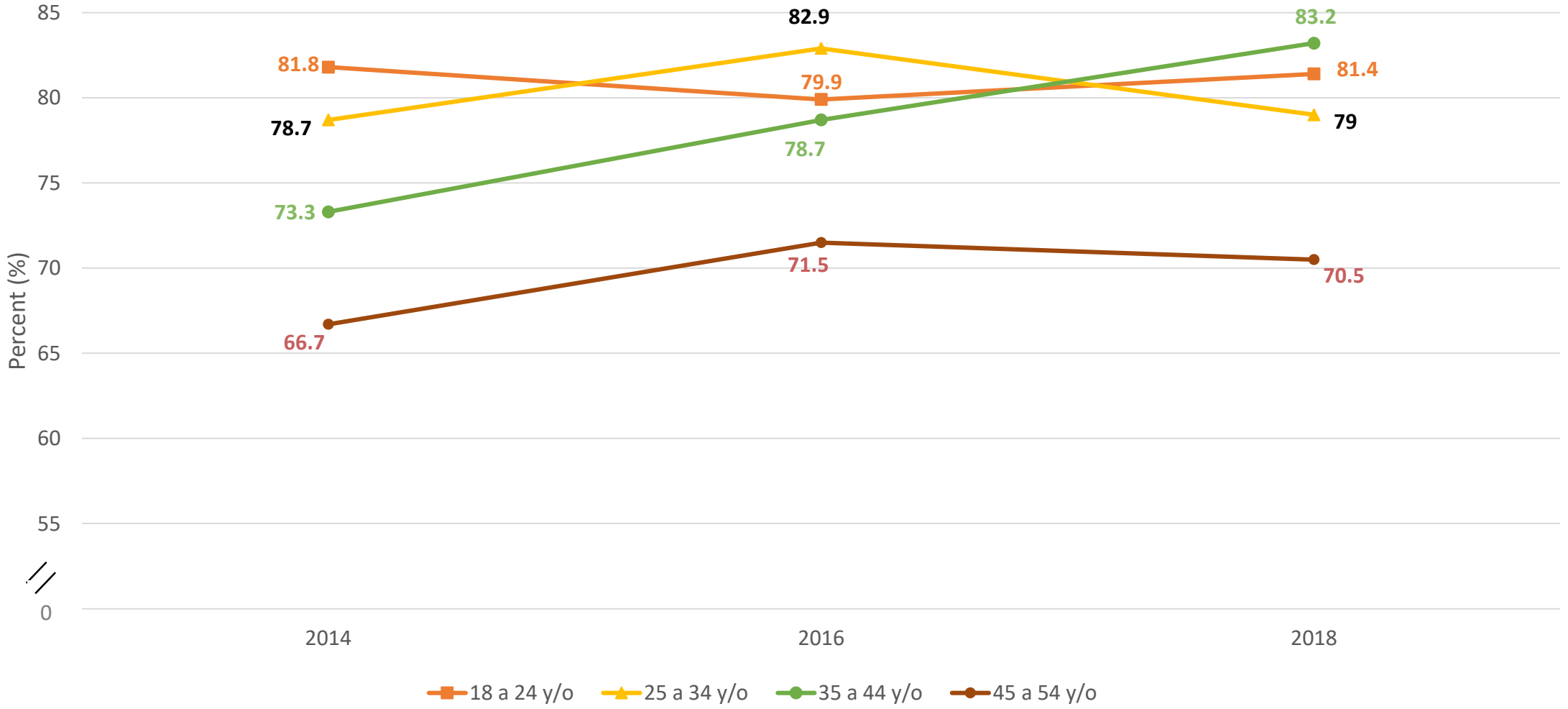
Source: PR-BRFSS, 2014 to 2018; PR Department of Health.

Figure 8: Women, by age group, ever told to have hypertension Puerto Rico: 2013 to 2017



Source: PR-BRFSS, 2013, 2015, 2017; PR Department of Health.

Figure 9: Women, by age group, that visited a dentist, dental hygienist, or dental clinic within the past year Puerto Rico: 2014 to 2016



Source: PR-BRFSS, 2014 to 2018; PR Department of Health.

Figure 10: Prenatal Care

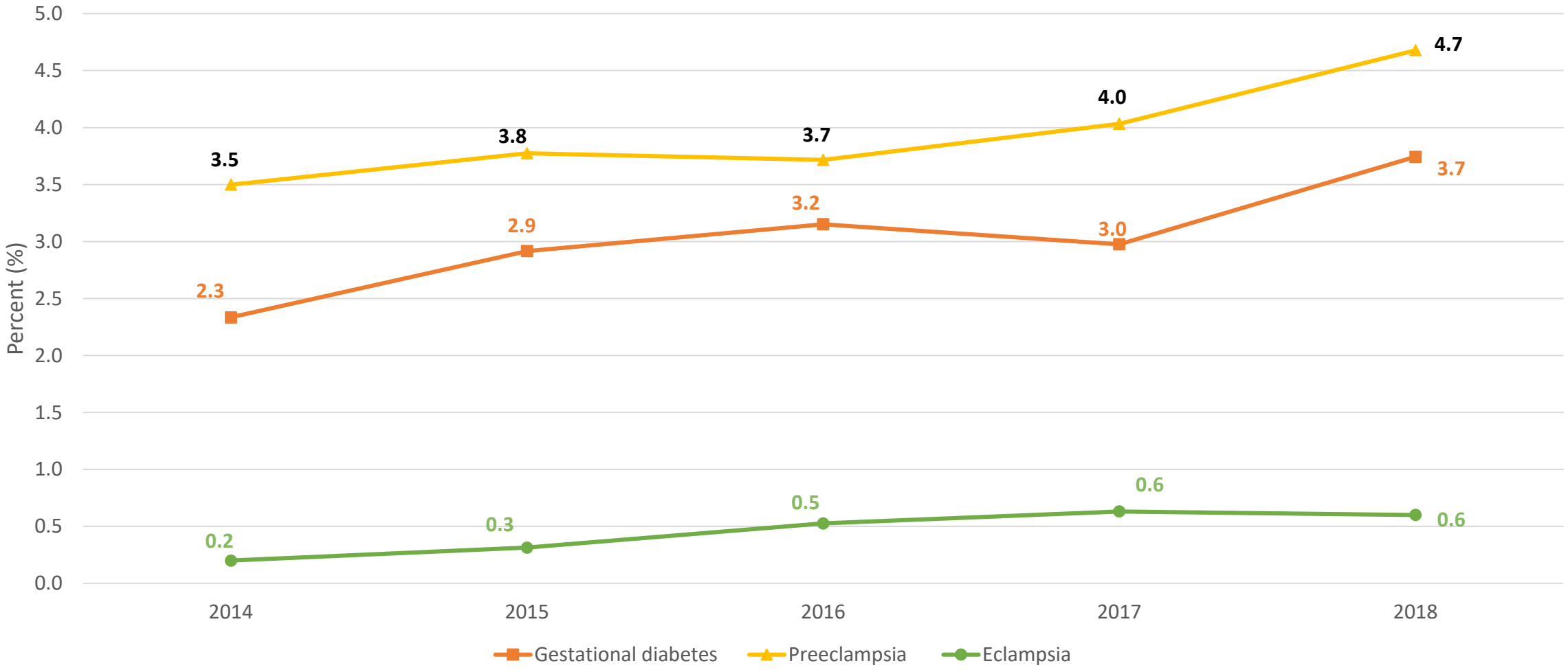
Puerto Rico Live Births: 2018

99.9% of women with a live birth received prenatal care.

83.2% initiated prenatal care during the first trimester.

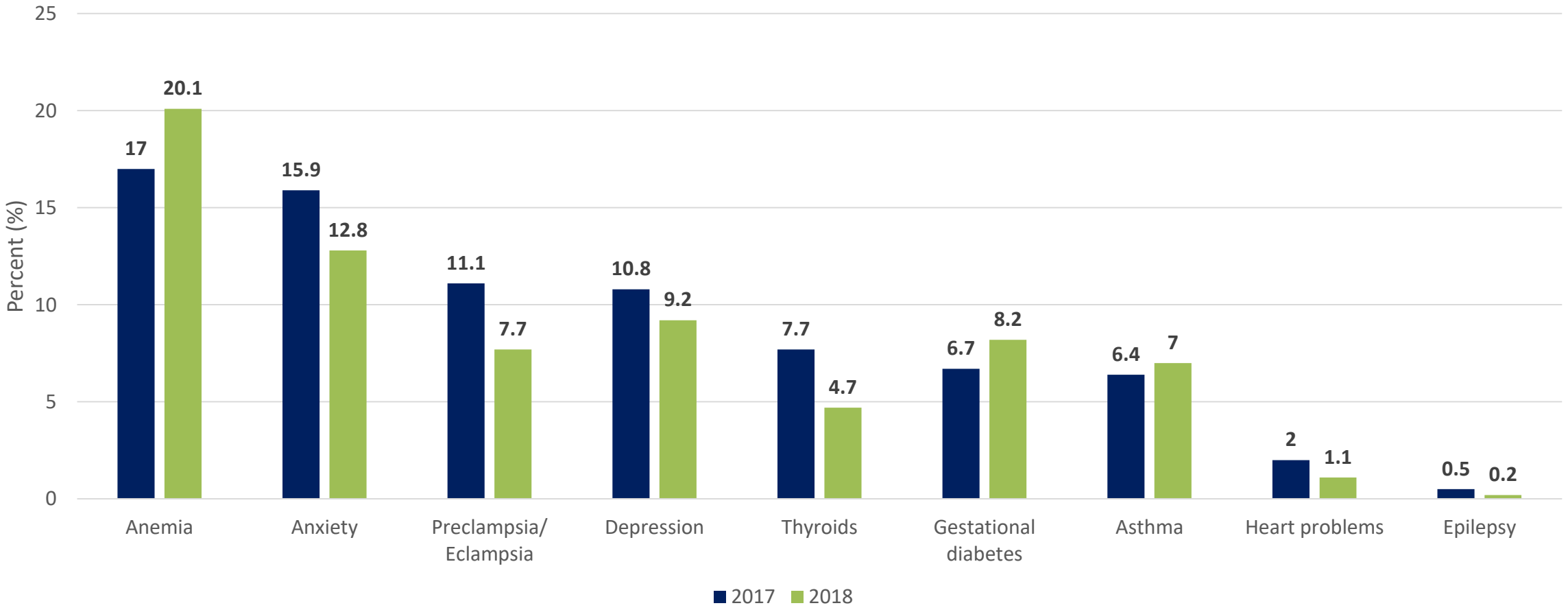
Source: Birth Certificate 2018. Demographic Registry and Vital Statistics. PR Department of Health.

Figure 11: Health conditions developed during pregnancy Puerto Rico: 2014 to 2018



Source: Birth Certificate 2014 to 2018. Demographic Registry and Vital Statistics. PR Department of Health.

Figure 12: Health conditions developed during pregnancy Puerto Rico: 2017 to 2018

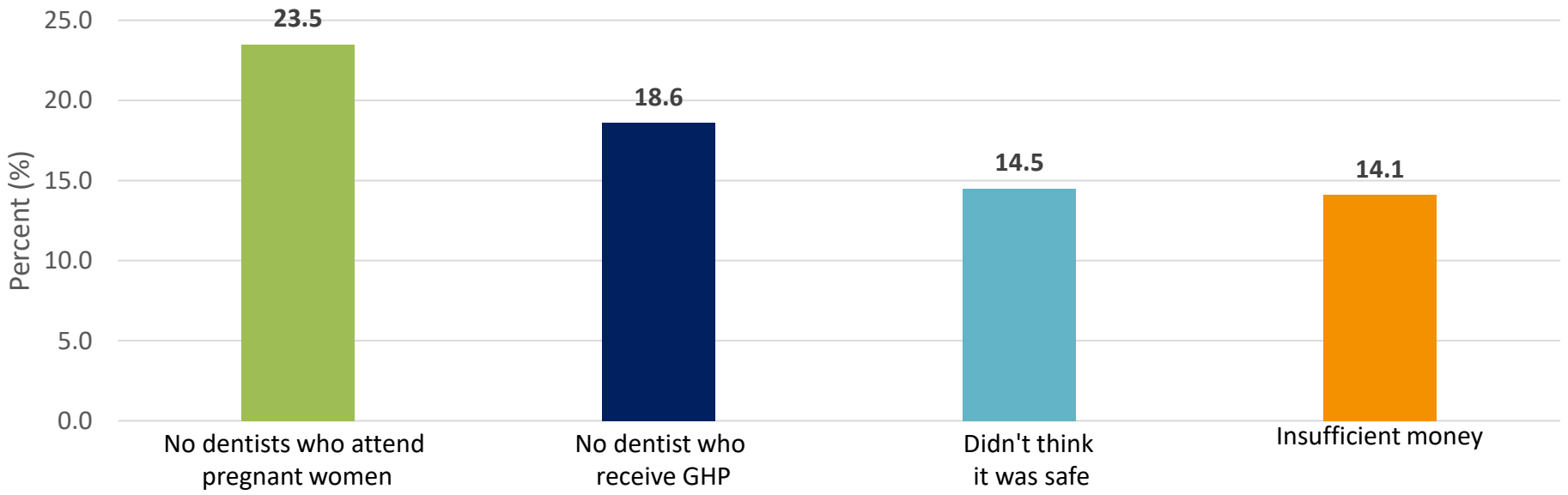


Source: PR-PRAMS 2017 & 2018; PR Department of Health.

Figure 13: Oral Health during pregnancy
Puerto Rico Live Births: 2018

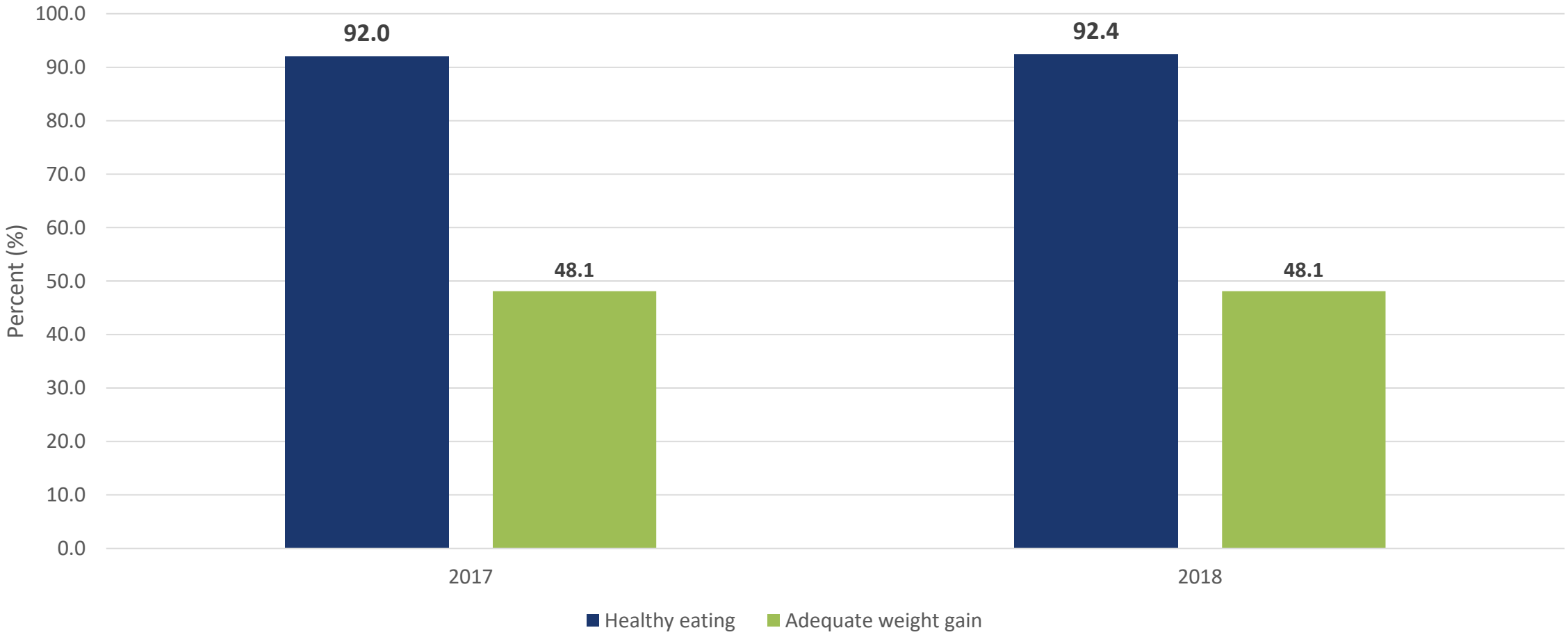
48.3% women with a live birth reported to visit a dentist or a hygienist for a routine dental cleaning visit.

Reasons why not going to a dental cleaning visit



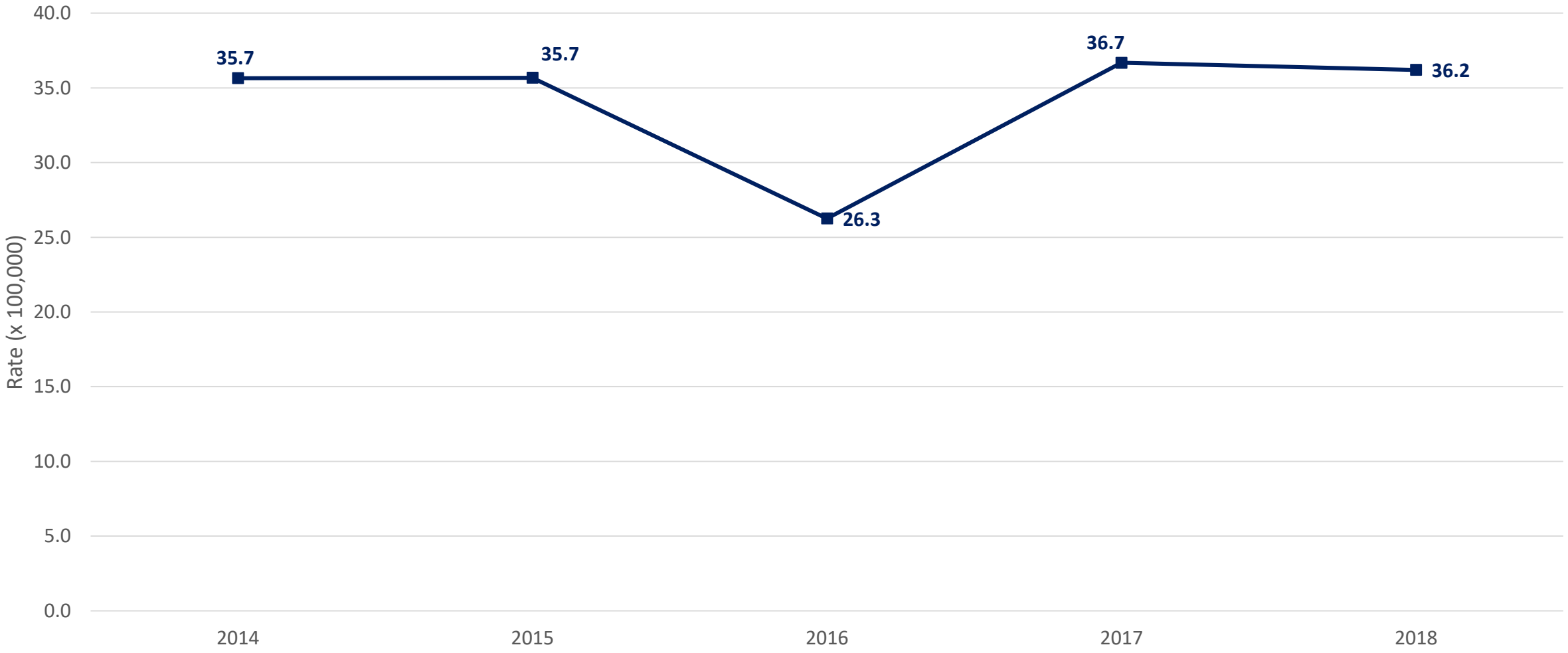
Source: PR-PRAMS 2018; PR Department of Health.

Figure 14: Education/orientation on healthy eating during pregnancy Puerto Rico: 2017 & 2018



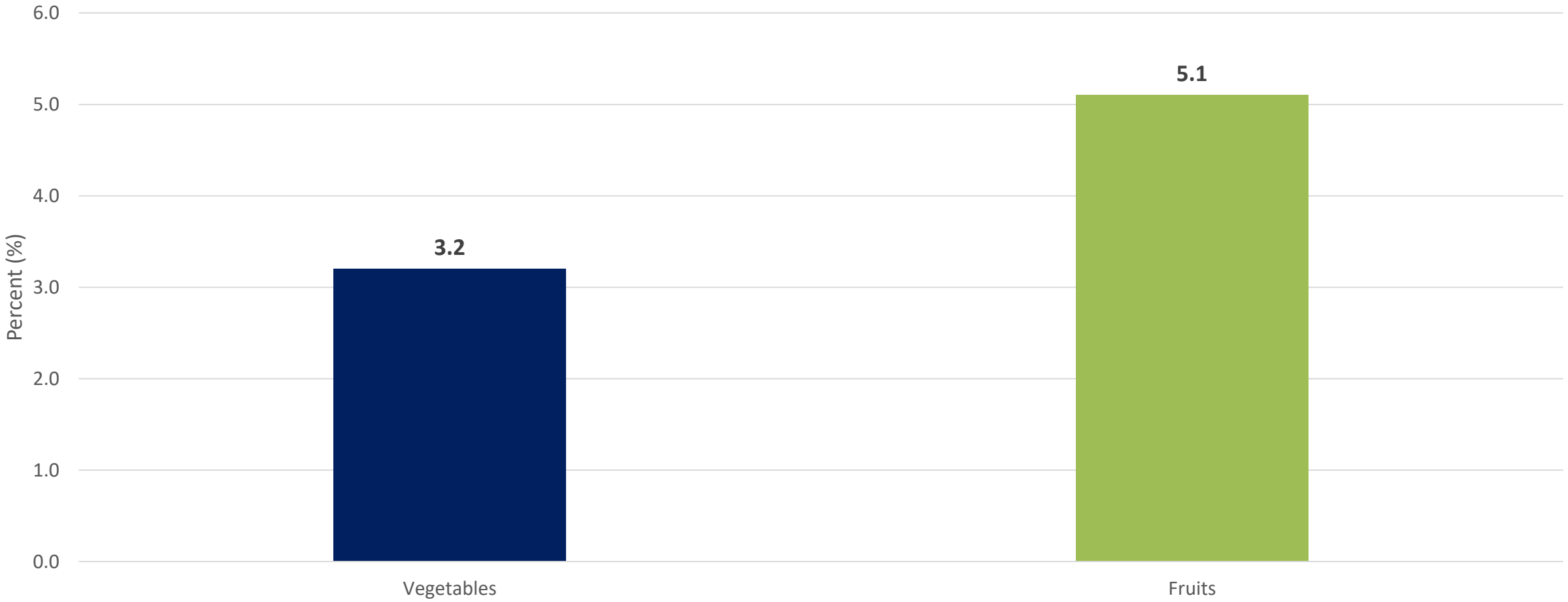
Source: PR-PRAMS 2017 & 2018; PR Department of Health.

Figure 15: Adequate weight gain in women that had a live birth Puerto Rico: 2014 to 2018



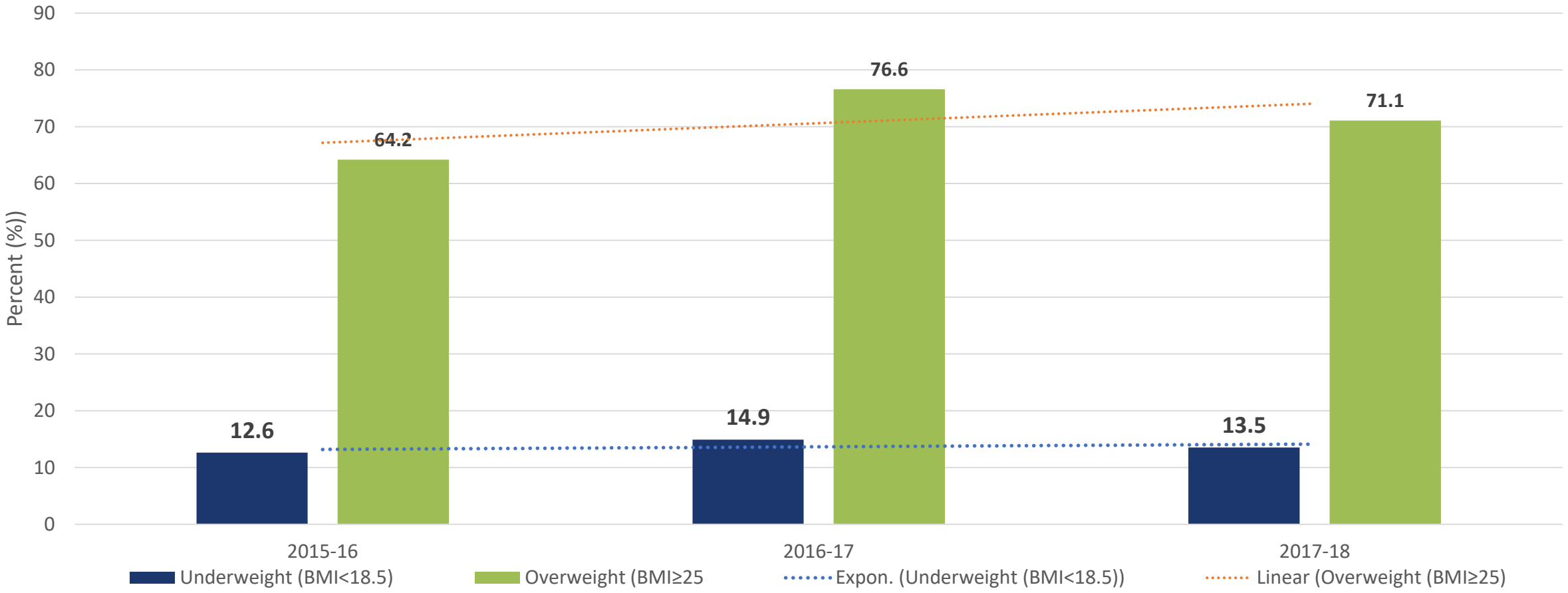
Source: Birth Certificate 2014 to 2018. Demographic Registry and Vital Statistics. PR Department of Health.

Figure 16: Vegetables and fruits consumption during pregnancy Puerto Rico: 2017



Source: PR-BRFSS 2017; PR Department of Health

Figure 17: Risk conditions (overweight and obesity) to participate in the WIC Program Puerto Rico: 2015-16 to 2017-18



Source: WIC Program, FY 2016-17 to 2017-18; PR Department of Health.

Maternal Voices

QUALITATIVE ANALYSIS OF PRPRAMS INTERVIEW BACK-PAGE COMMENTS

Figure 18: Qualitative Analysis of PRPRAMS telephone interview back-page comments

Purpose

To identify the concerns and situations raised by women in their back-page free comments.

Guiding Questions

- What issues do women bring up?
- How do women assess their experiences?
- What needs can be grasped from their comments?
- What implications do issues raised by women have for Title V?

Comments Analyzed

- 199 comments from batches 1-8 (2017). In Puerto Rico, PRAMS survey responses come mainly from telephone interviews

Figure 19: Qualitative analysis of PRPRAMS telephone interview back-page comments

Women framed their comments within the context of services (hospitals, medical providers, and government). They also framed their comments in terms of their concerns and what information and/or support they would had like to receive during pregnancy and immediately after giving birth. Furthermore, they framed their comments in relation to certain types of health behaviors during pregnancy to have a healthy infant.

FIVE main themes emerged from women's back-page comments

Figure 20: Maternal voices PRPRAMS Comments Themes

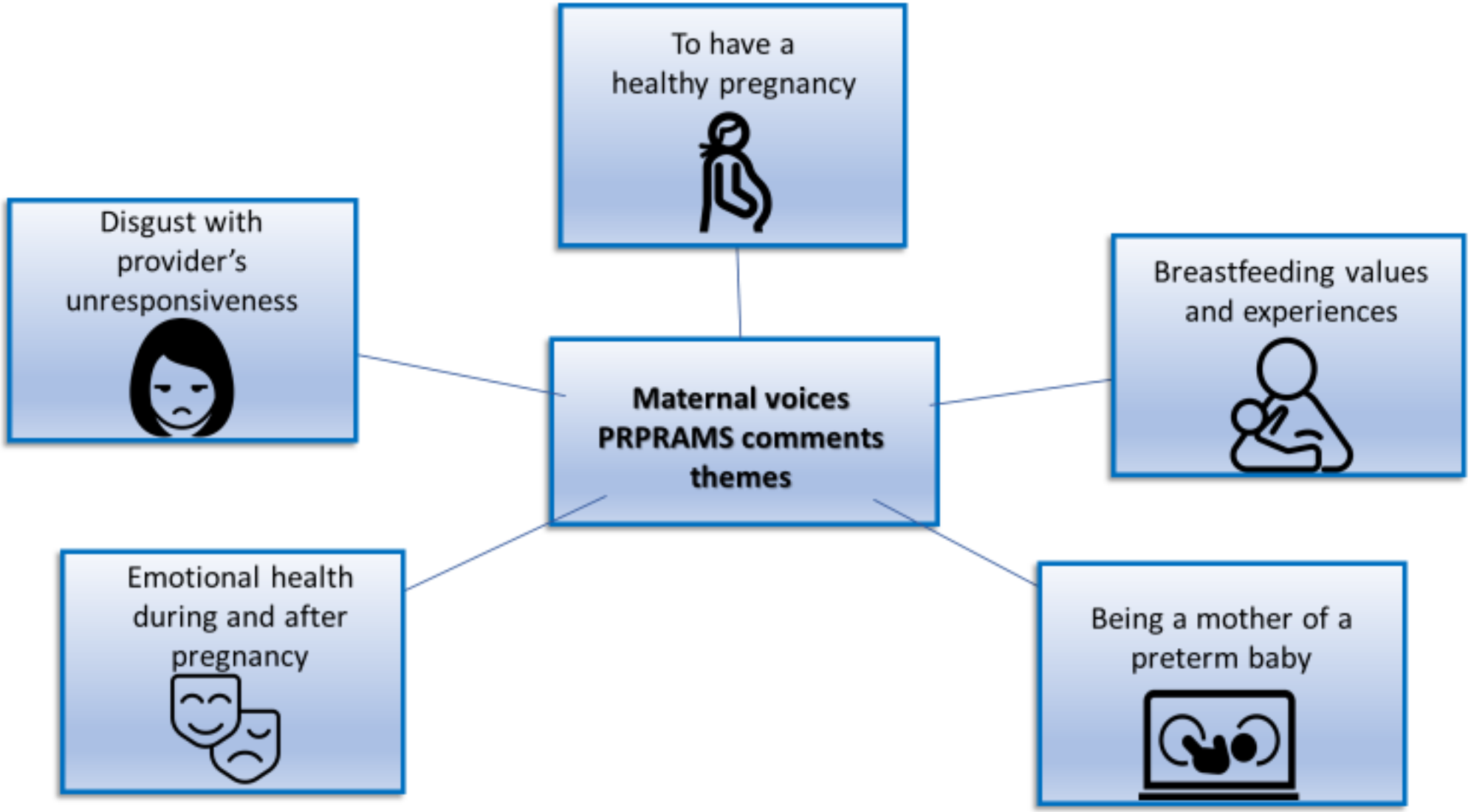


Figure 21: Qualitative analysis - To have a health pregnancy theme

According to women's comments a healthy pregnancy is related to nutrition, vitamin intake, prenatal care, being physically active, and avoiding harmful behaviors like smoking and alcohol use.

MATERNAL VOICES: QUALITATIVE ANALYSIS
TO HAVE A HEALTH PREGNANCY THEME

Figure 22: Maternal voices - o have health pregnancy theme

"Nutrition is especially important for the development of the baby as well as the prenatal vitamins. Also, not to consume alcohol or smoke cigarettes"

"They [women] must take care of themselves and they should go to the physician for the routine check-up. One should always have a routine check-up before and during [pregnancy] to have a better quality of life"

"What is most important to me is nutrition to have a healthy baby"

Figure 23: Qualitative analysis - Breastfeeding values and experiences theme

From women's comments, it can be said that they highly value breastfeeding. Women had high expectations for receiving breastfeeding information and support from nurses during their hospital stay. In the absence of support, women held negative views on hospitals and staff.

Figure 24: Maternal voices – Breastfeeding values and experiences theme

"The hospitals should be better informed. I had frictions with the nurses, they wanted to give the formula [to the baby]. They insisted a lot on using the formula. I think more workshops should be offered and to train them further"

"I am concerned about breastfeeding because I have seen that not everyone is pro-breastfeeding. There are nurses that force you to do things that are not correct. They want you to use the formula. There should be more orientation and they should be facilitators…They should be ready with information to help mothers"

"I understand that breastfeeding support is very important, especially to us first time mothers"

Figure 25: Qualitative analysis - Being a mother of a pre-term baby theme

This theme is about the experiences and feelings of women who delivered a preterm infant which can be a turning point in a woman's life and mothering trajectory. From their comments, having a premature infant is an extremely stressful and difficult life experience. To some mothers, it made them aware of the number of preterm babies born. Women also spoke about the need for more information about the signs of prematurity.

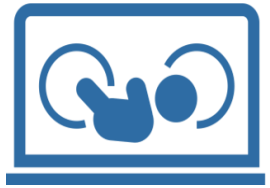


Figure 26: Maternal voices – Being a mother a pre-term baby theme

"They should have checkups if they feel any discomfort, consult the physician. Because I did not talk to my gynecologist nor I told him what I was feeling I had a premature delivery"

"During labor all was very anxious and very despairing; I gave birth at 29 weeks and it is difficult to process. It is an agony going each day to see my baby…later at home I had many fears"

"Something that impressed me were the premature babies in the NICU, they were too many"

BEING A MOTHER OF A PRE-TERM BABY THEME

Figure 27: Qualitative analysis - Emotional health during/after pregnancy theme

This theme is about the relevance of emotional health in the lives of women during pregnancy and after delivery. Economic hardships, C-Section, and high-risk pregnancy caused stress, anxiety, and emotional pain. Some women told about experiencing post-partum depression and need for understanding and support.

Figure 28: Maternal voices – Emotional health theme

"During the pregnancy I became very depressed because of the economic situation. My husband had no work…it was such a sadness because it was not easy, and I cried a lot"

"Sometimes motherhood is portrayed as something very beautiful, but the truth is that the first months are highly stressful, for example, postpartum depression. It is an awfully hard time. Here in Puerto Rico the topic is taboo. One feels very tired and stressed out…it is a grueling process and awareness should be raised about it"

"…the emotional health of the pregnant woman is not a priority. And one goes through many hormonal changes and nobody has the appropriate tools"

Figure 29: Qualitative analysis - Disgust with provider's unresponsiveness theme

Women brought up situations like unfair treatment, insensitivity, no response to their questions, and lack of support that caused strong disgust towards health service providers. Seemingly what women want is fair or respectful treatment, being listened to, and receiving answers to their questions.

Figure 30: Qualitative analysis disgust with provider's unresponsiveness theme

"Professionals should give better orientation to women. Sometimes one asks them questions and they don't know the answer"

"There is a lack of sensitivity on the part of physicians and I was traumatized by the cesarean, the physicians, and the nurses"

"The only thing that got me frustrated was the experience with those from the nursery and the hospital because I did not like the way they treated me, and I felt very uncomfortable…I think that mothers who had just given birth are more susceptible… They do not work with love" "

"I had made a birth plan, but they did not respect what I wanted. They trampled my body and my delivery. They assumed decisions that I did not take. It was an endless struggle with the professionals and physicians"

WRA KEY PERSON INTERVIEWS

PHASE ONE OF QUALITATIVE RESEARCH

ON THE HEALTH AND WELLBEING OF PRECONCEPTIVE YOUNG ADULT WOMEN AGED 21-34 IN PUERTO RICO

Figure 31: WRA key person interviews

Purpose

To obtain information based on first-hand experience and observations about the issues impacting preconceptive young adult women's (21-34 y/o) health and wellbeing in PR

Research Questions

- What health-related issues preconceptive young adult women face in present day PR?
- What are the social and health experiences of key persons along the life course?
- What are the views of key persons about health promotion among preconceptive WRA aged 21-34?

Key Persons

- Seven (7) women staff with no children from the Maternal, Child and Adolescent Division

Figure 32: WRA key person interviews
health and wellbeing of young adult women aged 21-34 in Puerto Rico

A key person is someone who has a special knowledge or unique perspective on the research subject and who is willing to share what she/he knows with the researcher. In this case, key persons as staff of the Maternal, Child and Adolescent Health Division, have public health knowledge and first-hand experience as women with no children.

Six main themes emerged from the key person interviews

Figure 33: WRA Key Interview Themes

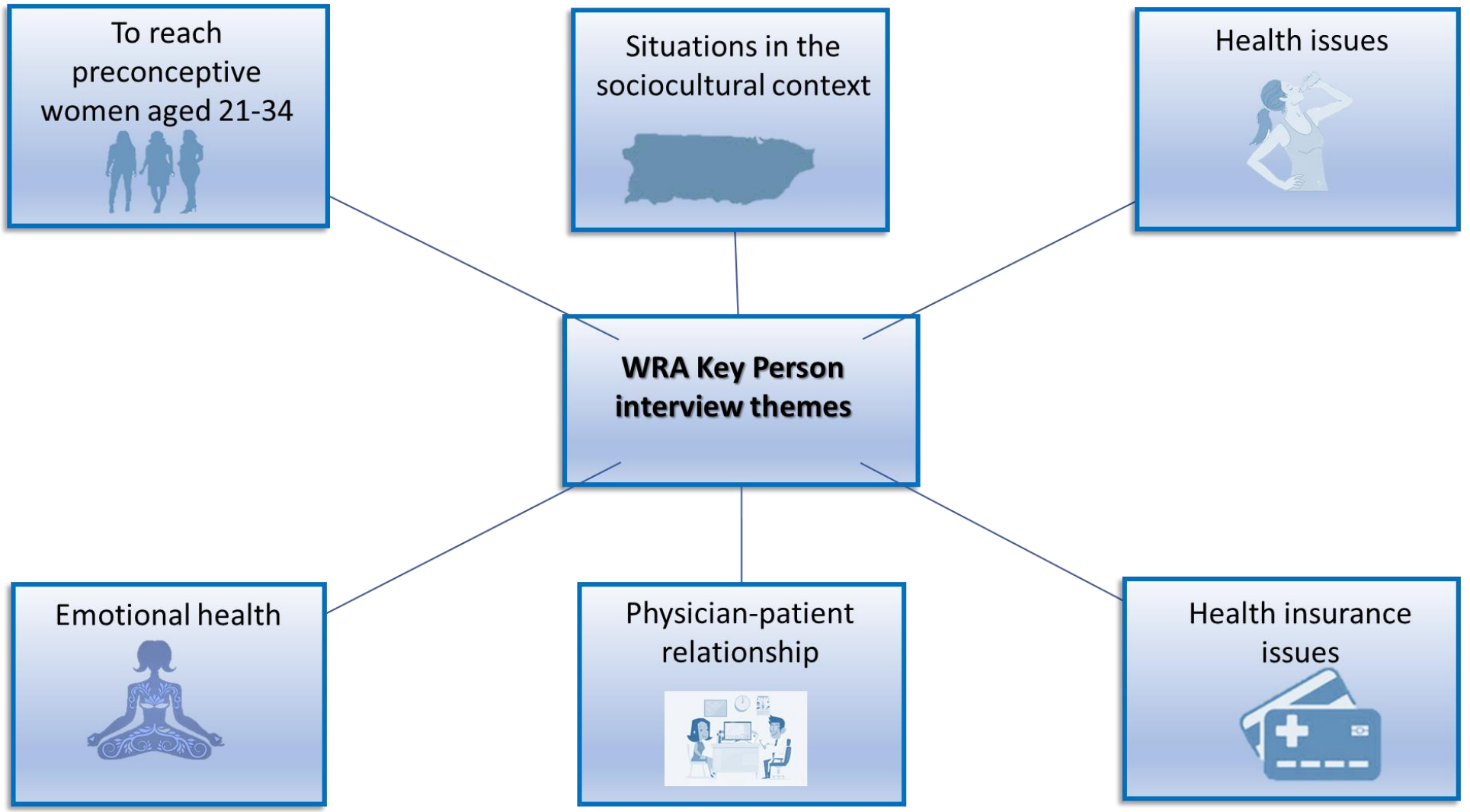


Figure 34: WRA key person interviews – Situations in sociocultural context theme

According to key persons preconceptive young adult women aged 21-34 face a myriad of economic, social, and cultural situations and challenges like low income, high cost of living, gender/age prejudice, and social pressure for motherhood in their daily lives.

Figure 35: WRA key person voices – Situations in sociocultural context theme

"...since I am young, they [former employers] saw me as having less value, as if I had no expertise at all. I have always given the maximum [extra mile] to show that I do have the capacity"

"To be an independent working woman is a bit challenging because the society, the community, and the people begin to question you: You don't have children? Are thinking to continue studying? Why?

"One can have a higher degree but really, they would never remunerate you according to whatever you studied. Everything goes up but the salaries remain low"

Figure 36: WRA key person interviews – Health issues theme

This theme is about situations related to the physical health of preconceptive young adult women aged 21-34 that include unhealthy eating; health conditions; inexistence of preventive visits; and lack of knowledge on existing services and women's health rights.

Figure 37: WRA key person voices – Health issues theme

"I am the typical [woman] that does not engage in preventive care. And that must be emphasized! I felt young, healthy, and did not think about anything. Then, one does not see it necessary to take care of oneself. But then, things like hypertension [may happen], a silent assassin"

"…I have tried to comply with my routine checkups because of my understanding of their importance after my work here at the Maternal, Child and Adolescent Division. I do not know what would have happened if I was not working here. Perhaps, I would be part of the percentage [of women] that do not see it as a priority [preventive visit]

"Well, the need is …to educate them about prevention so that they have the information on how to care for themselves, what health services are in the country…."

Figure 38: WRA key person interviews – Health insurance issues theme

Key persons pointed out that preconceptive young adult women (21-34 y/o) face barriers in accessing health care due to the high cost of health plans and deductibles, loss of parents' health plan at a certain age, and no coverage by the employer.

Figure 39: WRA key person voices – Health insurance issues theme

"I had no medical plan from 2015 to 2018…because medical plans are vey costly….and they charge you high deductibles"

"…the search for health services is exceedingly difficult. First, the issue of medical insurance, if you have one……at age 26 one has to withdraw from the family's plan…then you have to pay for your own health plan and medical plans are very expensive if one does not qualify for the reform [government health plan]…I was without a health plan for a couple of months"

Figure 40: WRA key person interviews – Physician-patient relationship theme

Key persons spoke about the need for respectful, sensitive and open communication. They advocate for what the literature calls "person-centered care" that entails seeing patients as partners, being responsive to their needs and values, and engaging them in health decision making. This type of relationship may possibly help to promote preventive visits.

Figure 41: WRA key person voices – Physician-patient relationship theme

"There has to be something that engages them…the physician-patient relation should be friendly as much as possible, so that she becomes aware of the importance of visiting the doctor and comply with all the requirements of the preventive checkup"

"There is the issue of respect for women's decisions. They should not think that just because one is young means that one lacks good judgment, and to really respect my decisions. That I can ask questions without feeling that I am overburdening the physician"

"I think that besides offering good talks so that women take care [of health] …physicians should be more emphatic."

Figure 42: WRA key person interviews – Emotional health theme

According to key persons situations such as fast pace of life, economic responsibilities, combining work and study, and social pressure to have children often leads to anxiety and stress among young adult women (21-34 y/o) with no children.

Figure 43: WRA key person voices – Emotional health theme

"There is a lot of stress, a lot of anxiety. At the university I have seen my younger classmates already burden and they expressed it. I went through that!

"At least in my own case, I cannot fall behind my work because it must be up to date. That causes a lot of stress. Later, when one goes home and then you have your home stress; we do not t have this, we must buy this, the car broke down. These are the daily life stressors"

"…We are living in such times that mental health should be given priority. How to manage stress should definitively be promoted."

Figure 44: WRA key person interviews – To reach preconceptive women aged 21-34 theme

This theme refers to promoting health among pre-conceptive young adult women aged 21-34. The key persons suggested strategies concerning the issues they raised that the MCAH Program could use to promote health and wellbeing in this segment of the WRA population. Some noted the invisibility of this WRA segment in public health.

TO REACH PRECONCEPTIVE WOMEN AGED 21-34 THEME

Figure 45: WRA key person voices – To reach preconceptive women aged 21-34 theme

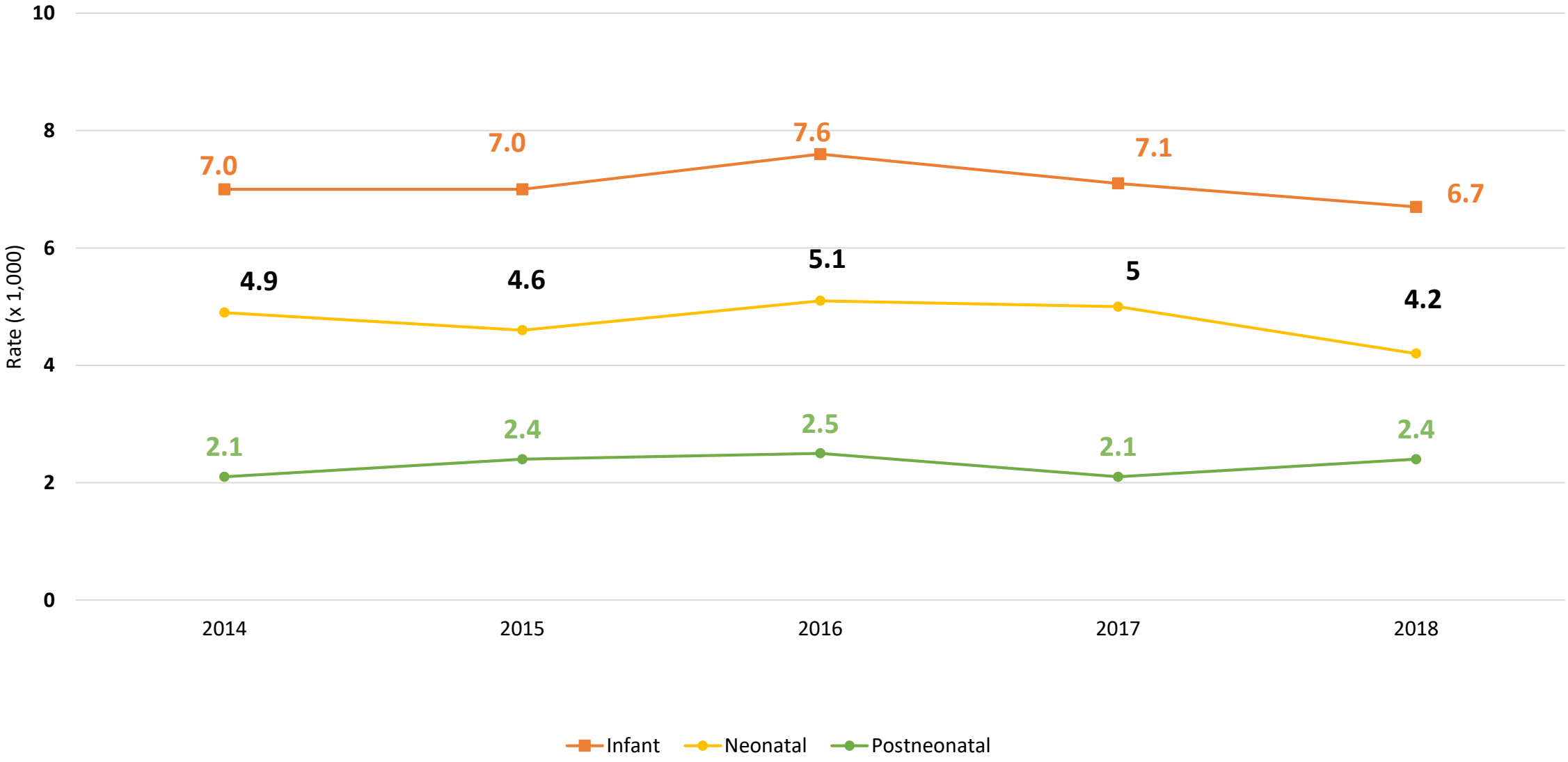
"It is not a population that one mentions a lot, including us here at the Division. We always focus on the pregnant woman because one has to take care of the pregnancy, then the baby, then the child and then the adolescent. But, what about her? [woman 21-34 y/o].

"I think that women of this age [group] should be offered more education. Thinking about it from the field, perhaps to create some type of project…because we focus on pregnant women, the babies, or mothers…but these young women like me, where do they receive education? Some type of project that focus on women at this age stage"

"Well, we should do first this type of effort [research] to see what we need because we do not even consider ourselves. Right now, while talking to you is that I have become aware that even us [MCAHD] have no initiative…"

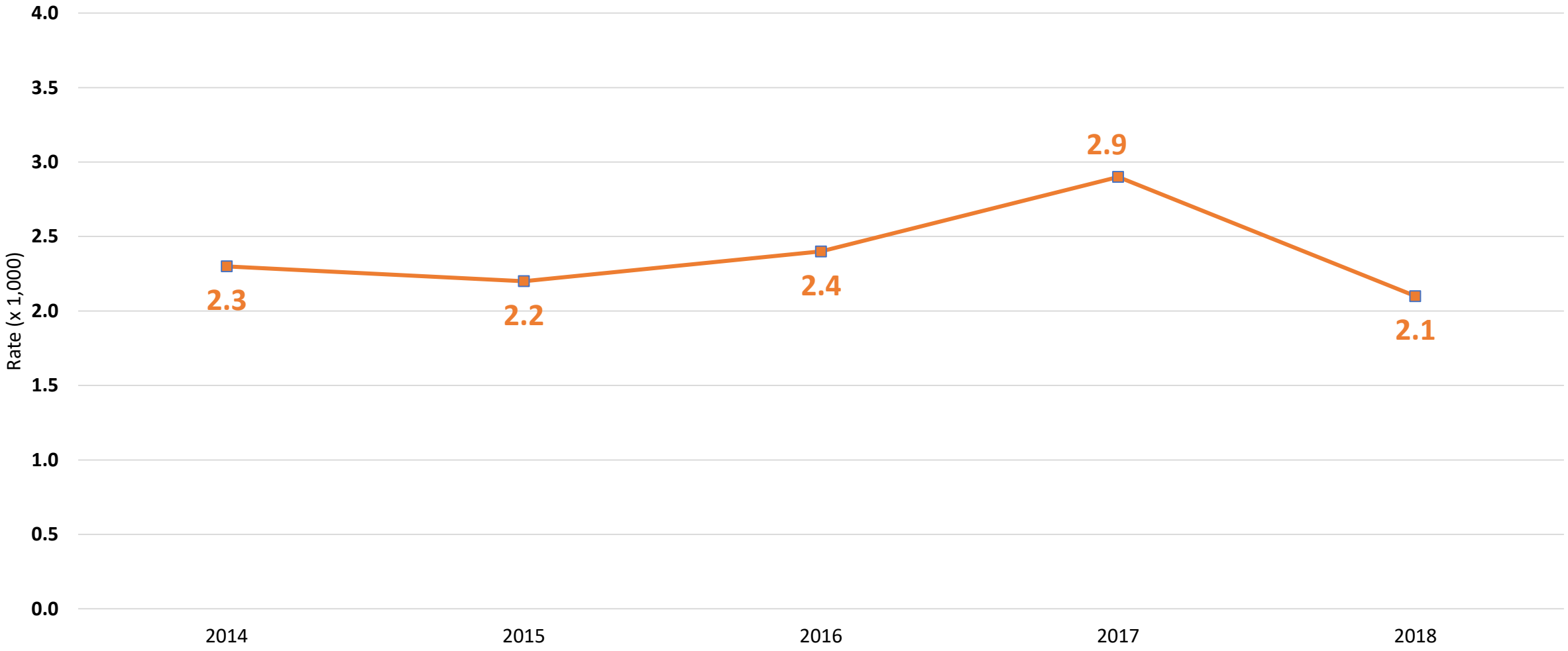
Perinatal/Infant Health

Figure 46: Infant, Neonatal and Postneonatal Mortality Puerto Rico: 2014 to 2018



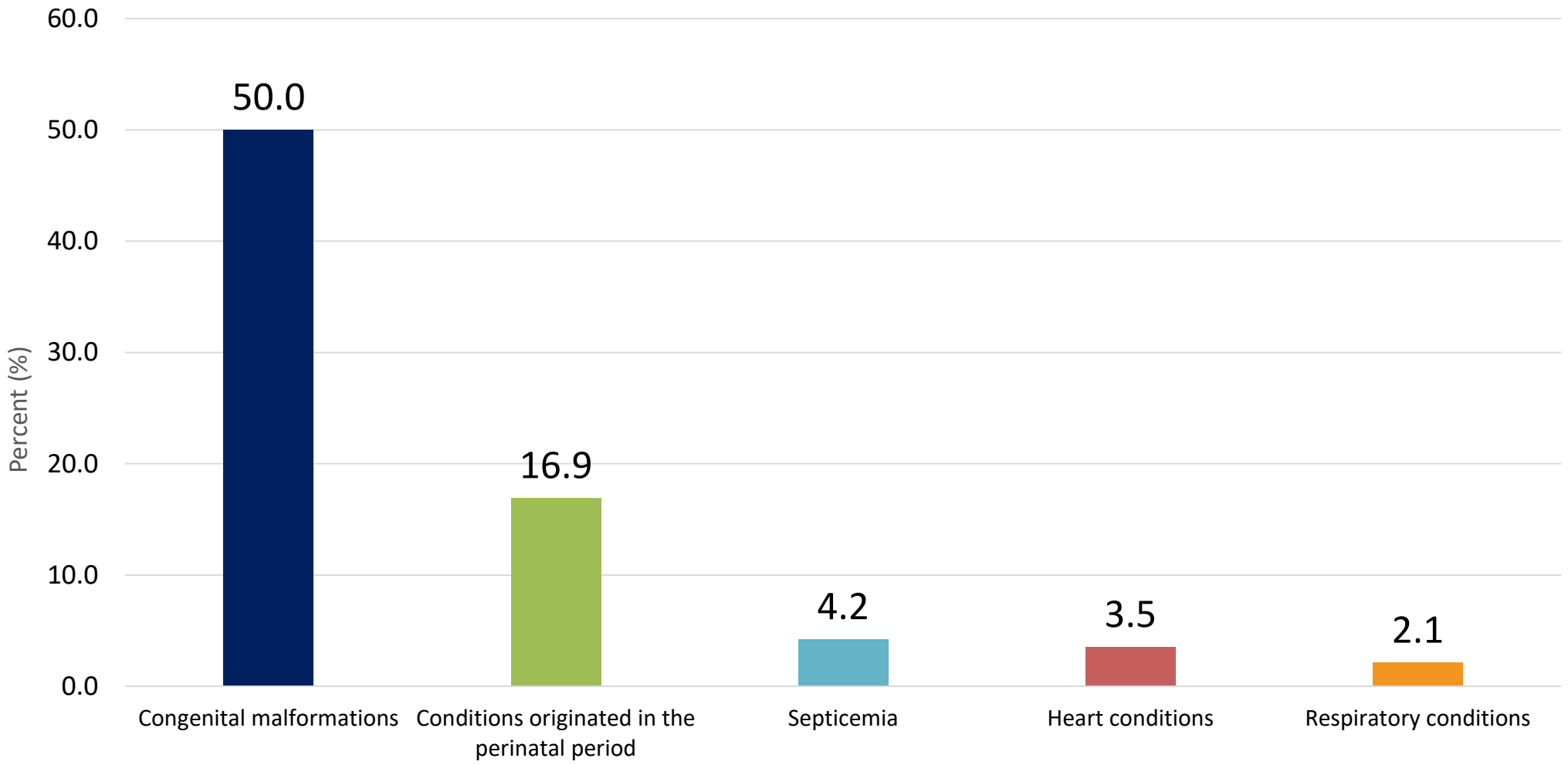
Source: Birth and Death Certificates 2014 to 2018, Demographic Registry and Vital Statistics; PR Health Department.

Figure 47: Infant mortality rates related to prematurity
Puerto Rico: 2014 to 2018



Source: Birth and Death Certificates 2014 to 2018, Demographic Registry and Vital Statistics; PR Health Department.

Figure 48: Top five infant mortality causes Puerto Rico: 2018



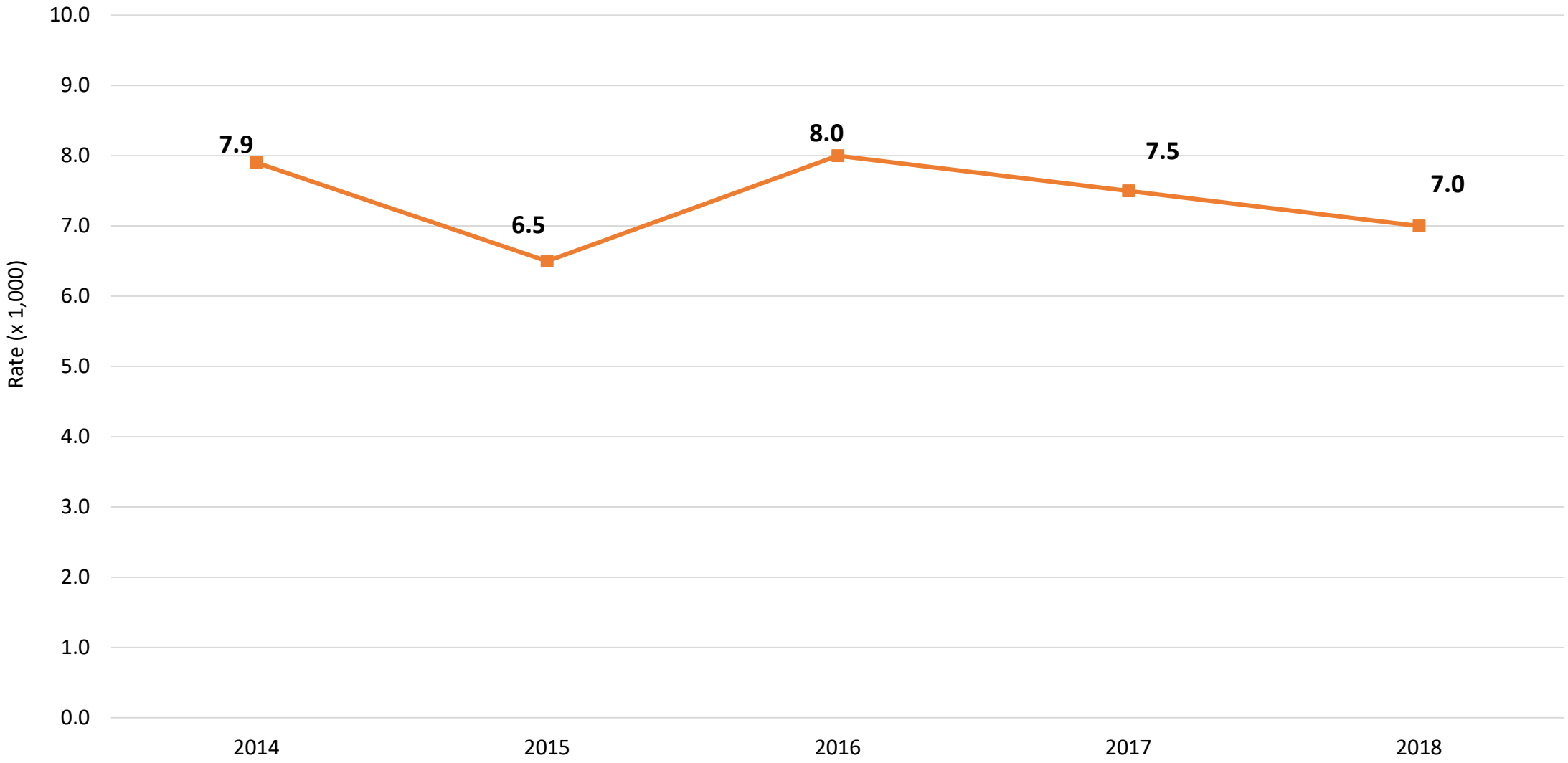
Source: Death Certificates 2018, Demographic Registry and Vital Statistics; PR Health Department.

Figure 49: Developmental (ASQ-3) and socio-emotional (ASQ: SE-2) screening Puerto Rico: Title V Home Visiting Program 2018

	n	%
Infants/pediatric total screening	1409	100
Low risk screening results	1306	92.7
High risk screening results	103	7.3
Referrals required due to screening results or parental concern	103	100
Early Intervention	88	85.4
Pediatric Centers	8	7.8
FASES	3	2.9
Children with special medical needs	1	1.0
Zika Program	2	1.9
Referral disposition	103	100
Referral completed	84	81.6
Referral not completed	12	11.7
Refuse the referral	1	0.1
Did not qualify for services referred to	6	6

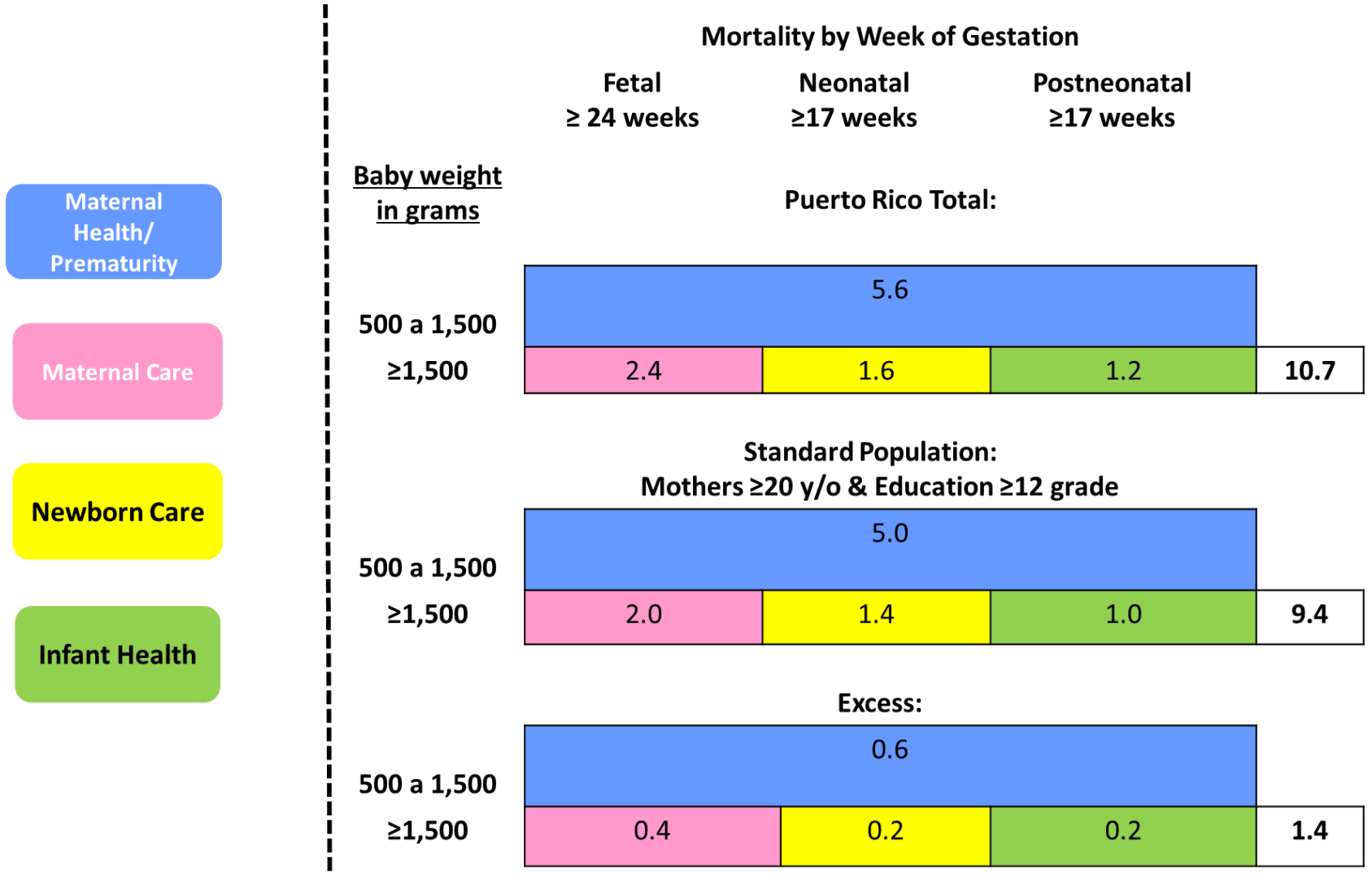
Source: Title V Home Visiting Program 2018.PR MCAH Program; PR Department of Health.

Figure 50: Perinatal Mortality
Puerto Rico: 2014 to 2018



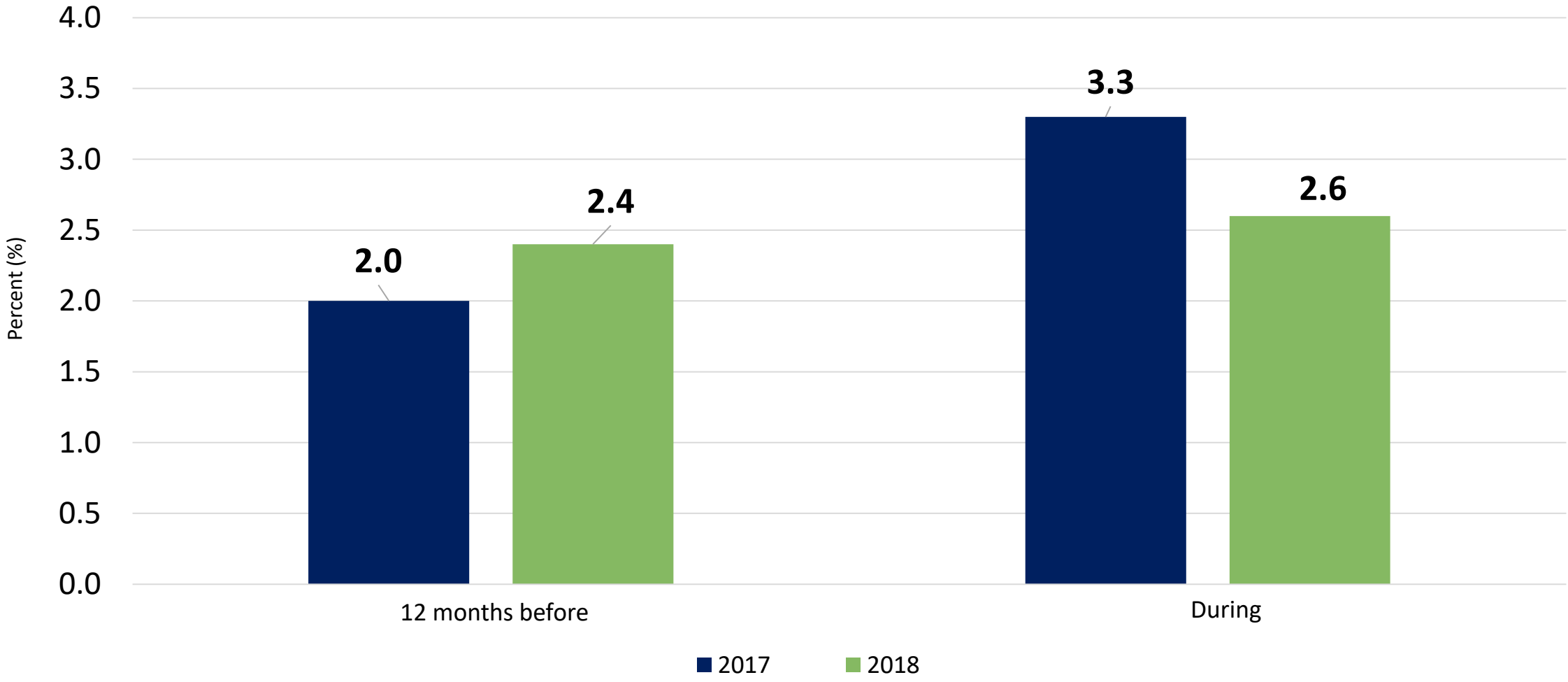
Source: Birth, Fetal, and Death Certificates 2014 to 2018, Demographic Registry and Vital Statistics; PR Health Department.

Figure 51: Perinatal Periods of Risk (PPOR)
PR: 2015 to 2018



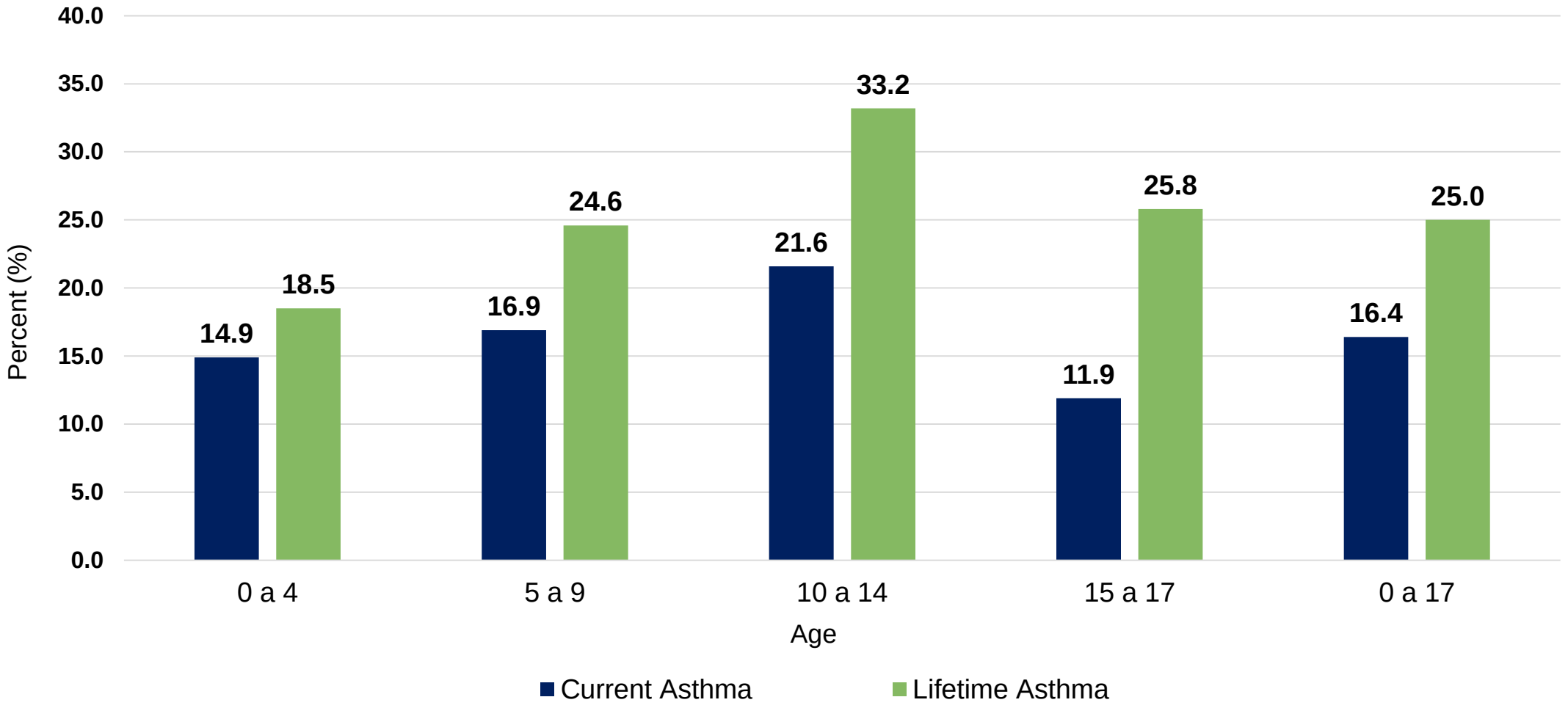
Source: Birth, Fetal, and Death Certificates 2015 to 2018, Demographic Registry and Vital Statistics; PR Health Department.

Figure 52: Women with live births that reported being physically abused by someone
Puerto Rico: 2017 to 2018



Source: PR-PRAMS, 2017 to 2018; PR Department of Health.

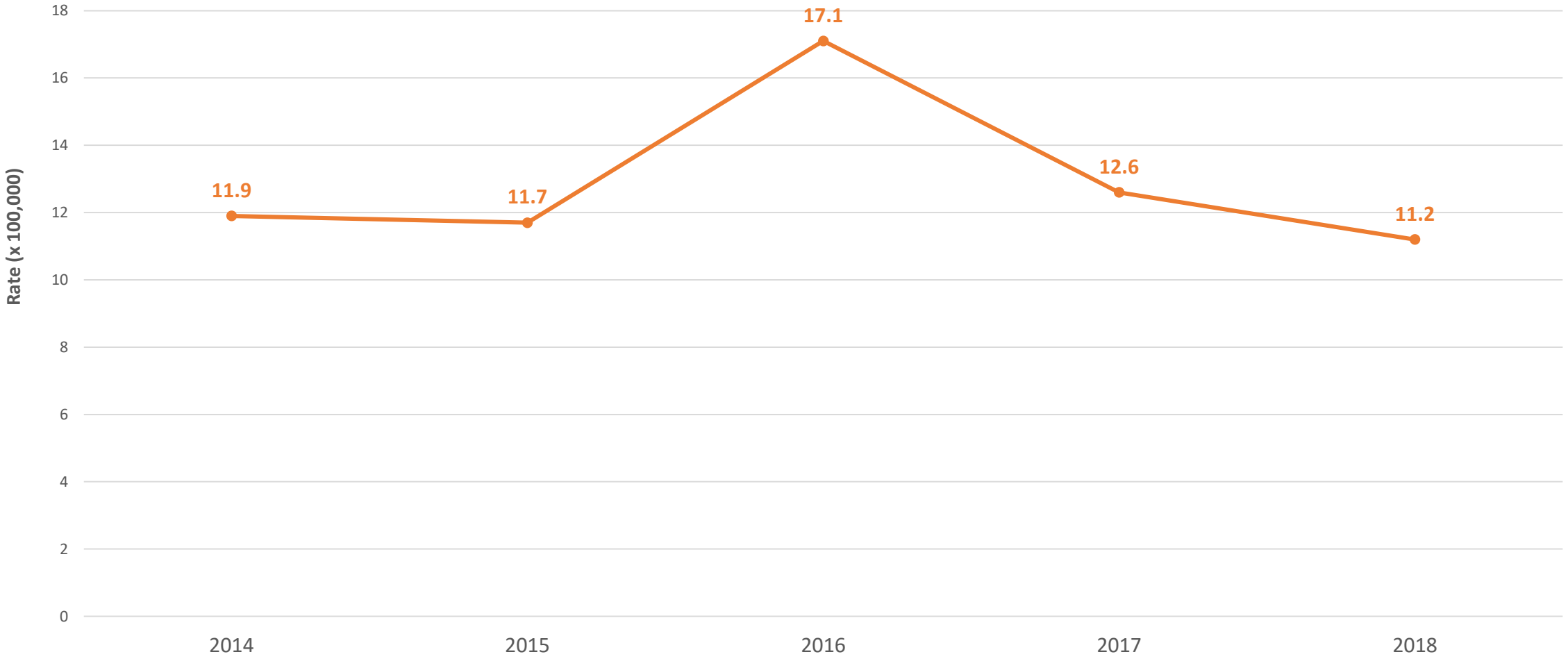
Figure 53: Current and lifetime asthma prevalence by age group Puerto Rico: 2015 to 2017



Source: Asthma Burden Report, PR Asthma Program de Puerto Rico, PR-BRFSS, 2015-2017; PR Department of Health.

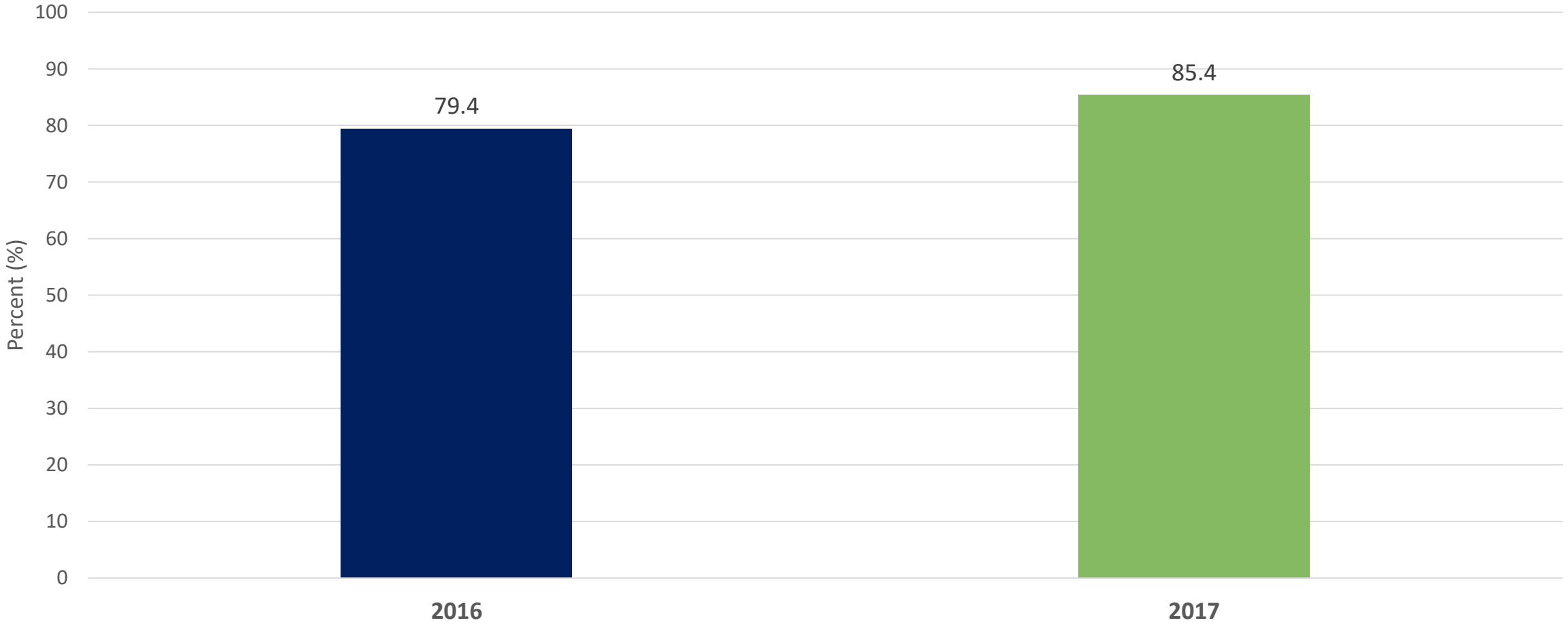
Child Health

Figure 54: Child 1 to 9 years old mortality rate
Puerto Rico: 2014 to 2018



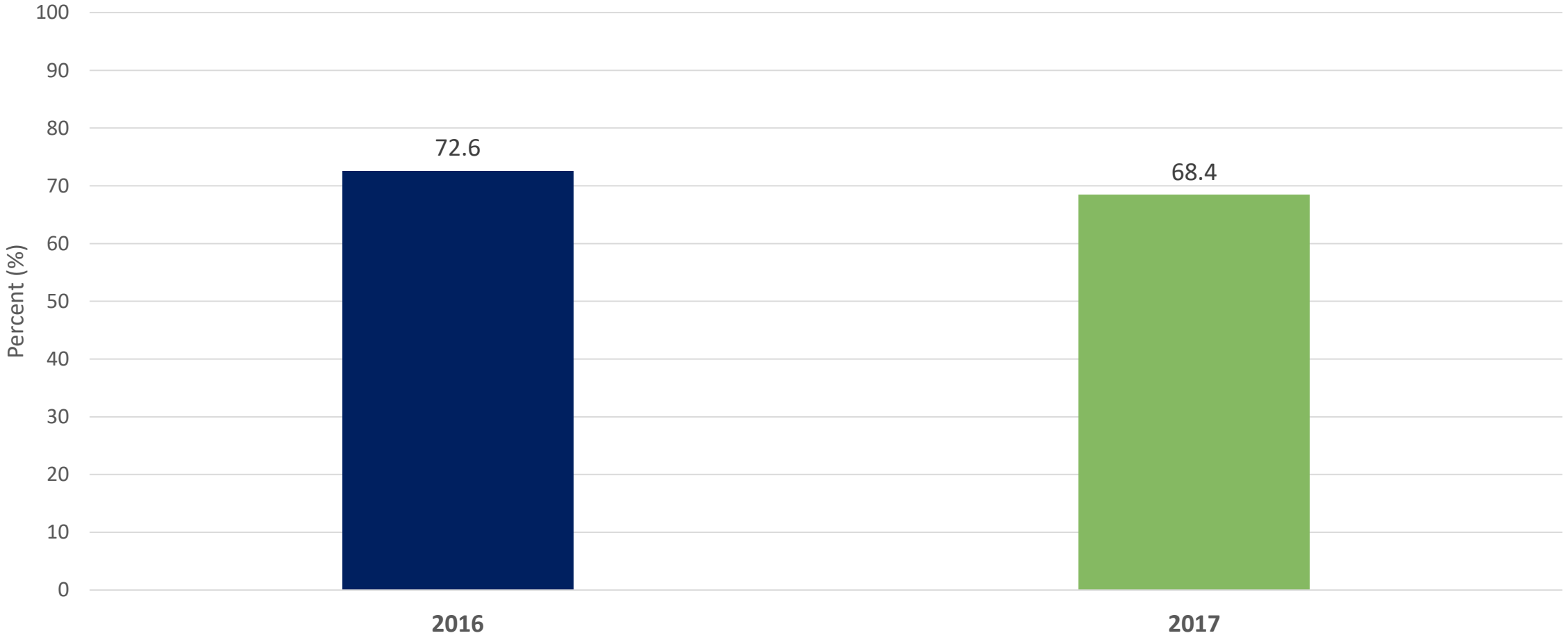
Source: Death certificate 2014 to 2018. Demographic Registry and Vital Statistics. PR Department of Health.

Figure 55: Children 1 to 11 years old with a medical preventive visit on the last year Puerto Rico: 2016 & 2017



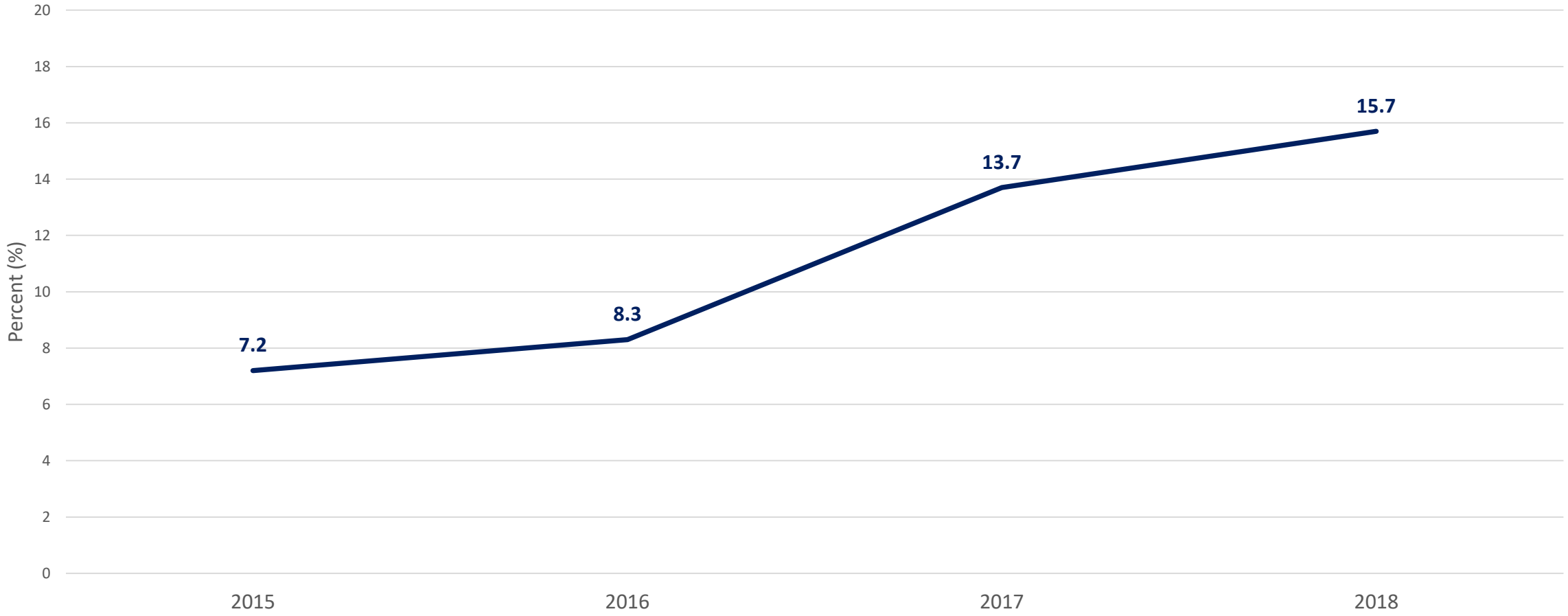
Source: PR-BRFSS 2016 & 2017. PR Department of Health.

Figure 56: Children 1 to 11 years old with a preventive oral visit on the last year Puerto Rico: 2016 & 2017



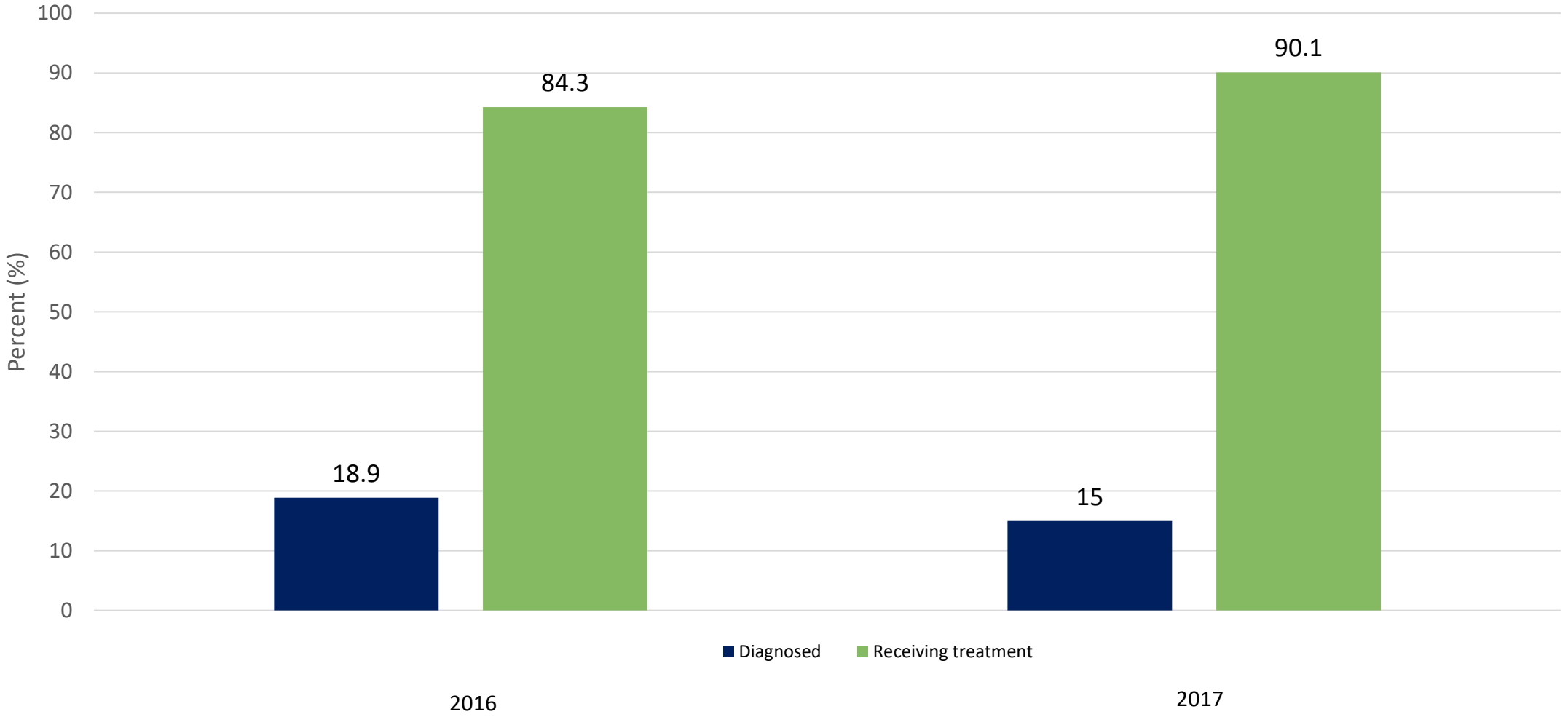
Source: PR-BRFSS 2016 & 2017. PR Department of Health.

Figure 57: Children 1 to 11 years old with treated dental caries Puerto Rico: 2015 to 2018



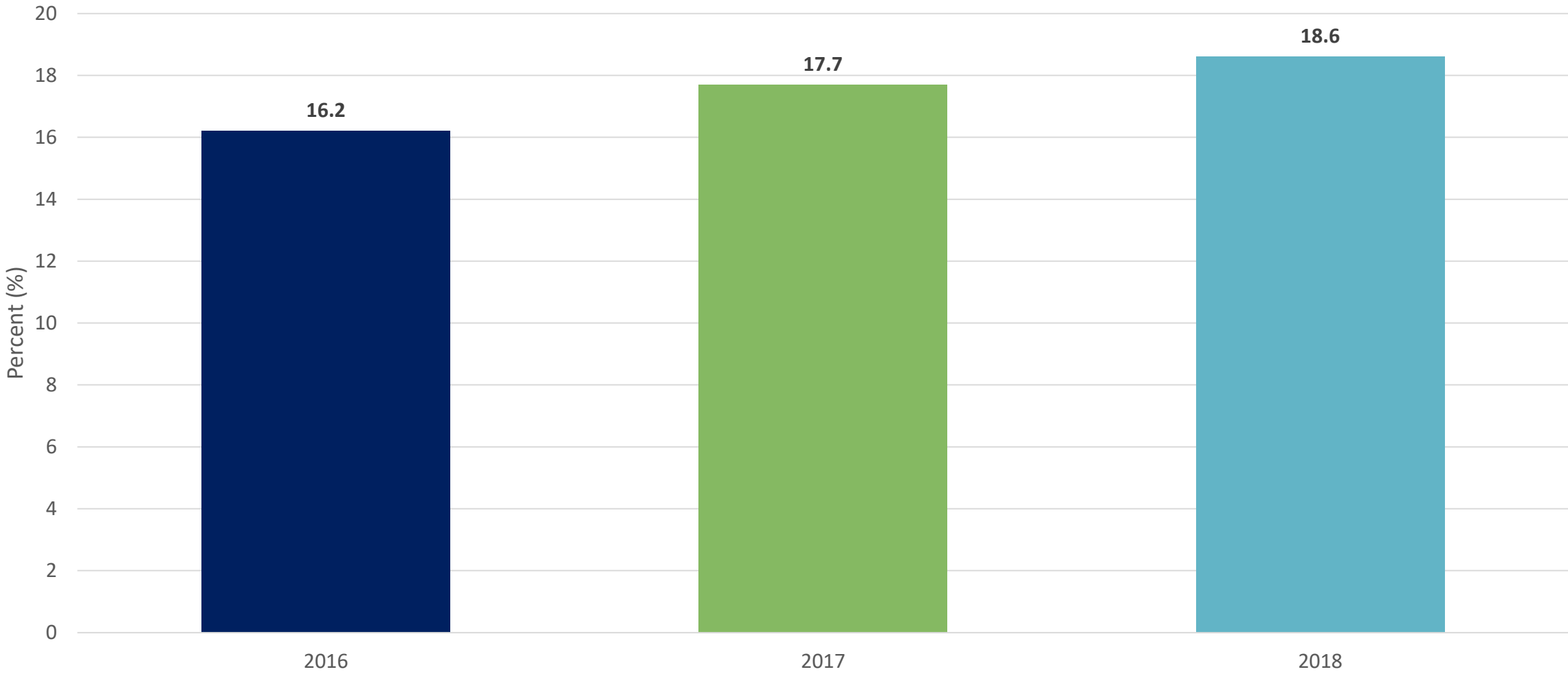
Source: PR Health Insurance Commissioner Office and PR Health Insurance Administration 2015 to 2018.

Figure 58: Children 1 to 11 years old diagnosed with depression, anxiety or behavioral problems and received treatment Puerto Rico: 2016 & 2017



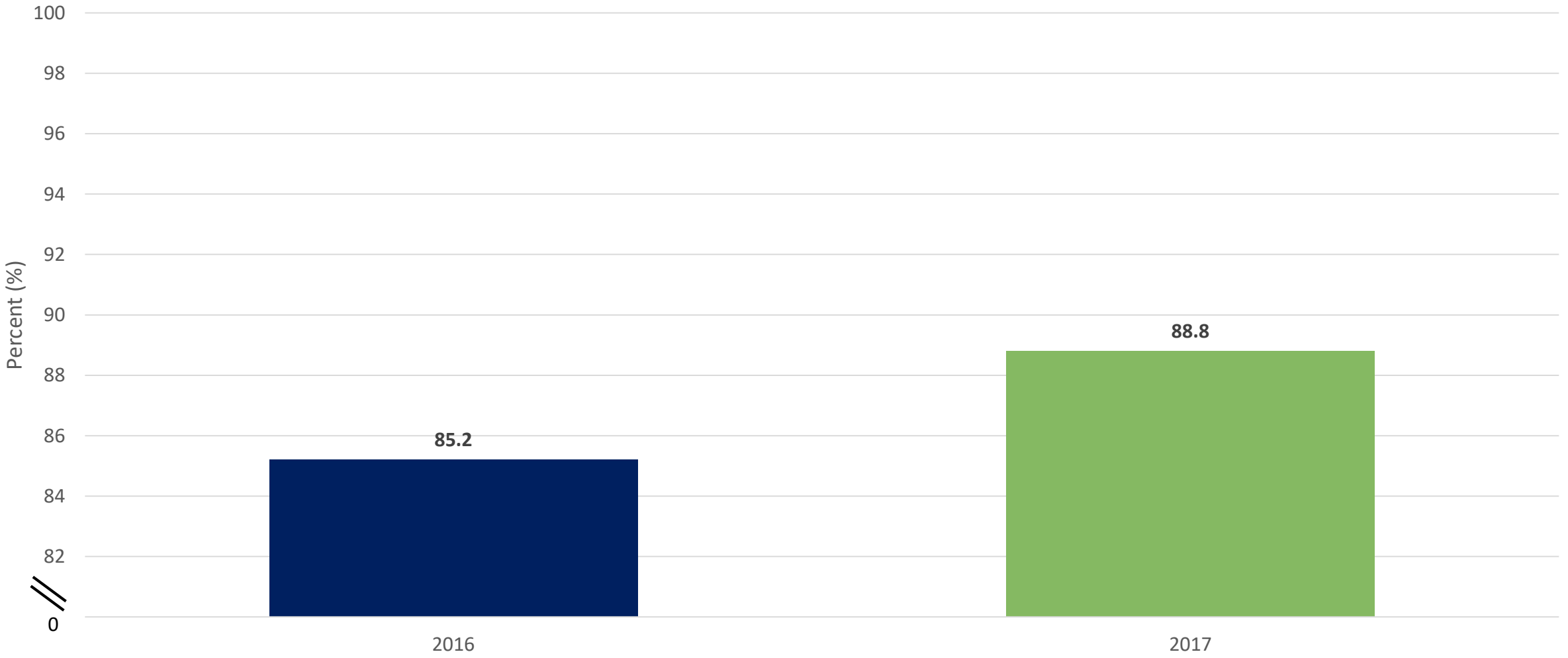
Source: PR-BRFSS 2016 & 2017. PR Department of Health

Figure 59: Program 2 to 5 years old participants with BMI ≥ 85 Puerto Rico: 2016 to 2018



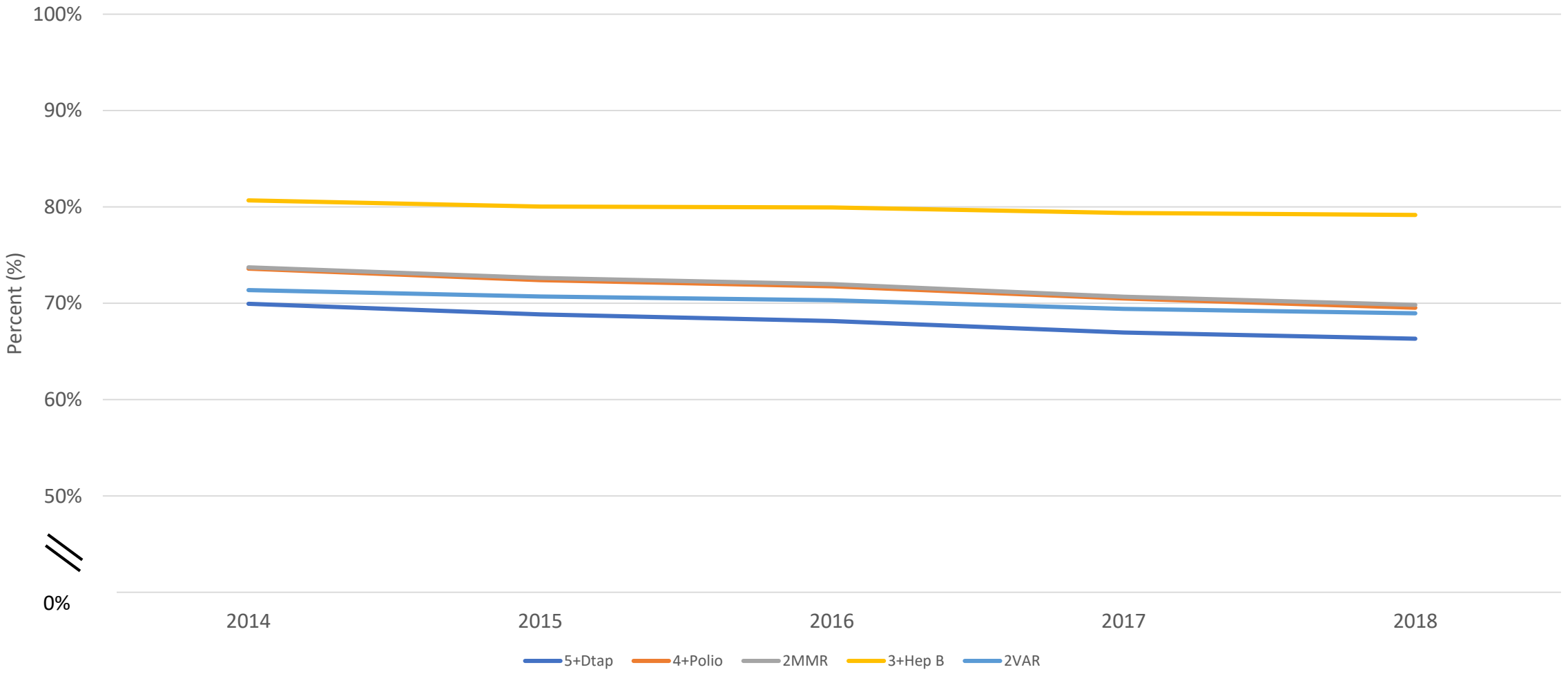
Source: WIC Program 2016 to 2018. PR Department of Health

Figure 60: Children 1 to 11 years old that are physically active at least 60 minutes a day Puerto Rico: 2016 & 2017



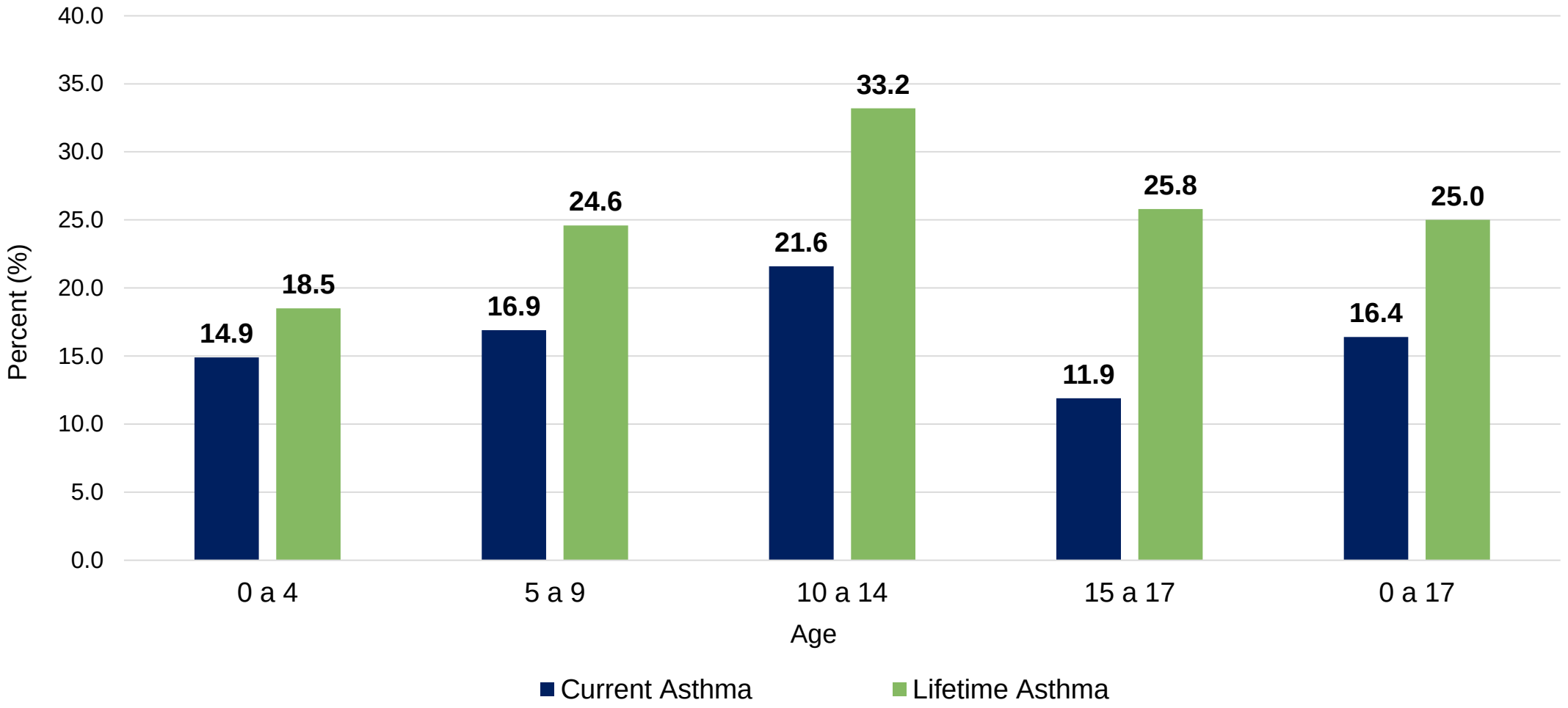
Source: PR-BRFSS 2016 & 2017. PR Department of Health.0

Figure 61: Immunization prevalence in children 6 to 1o years old Puerto Rico: 2014 to 2018



Source: PR Immunization Registry 2014 to 2018. PR Departtment of Health.

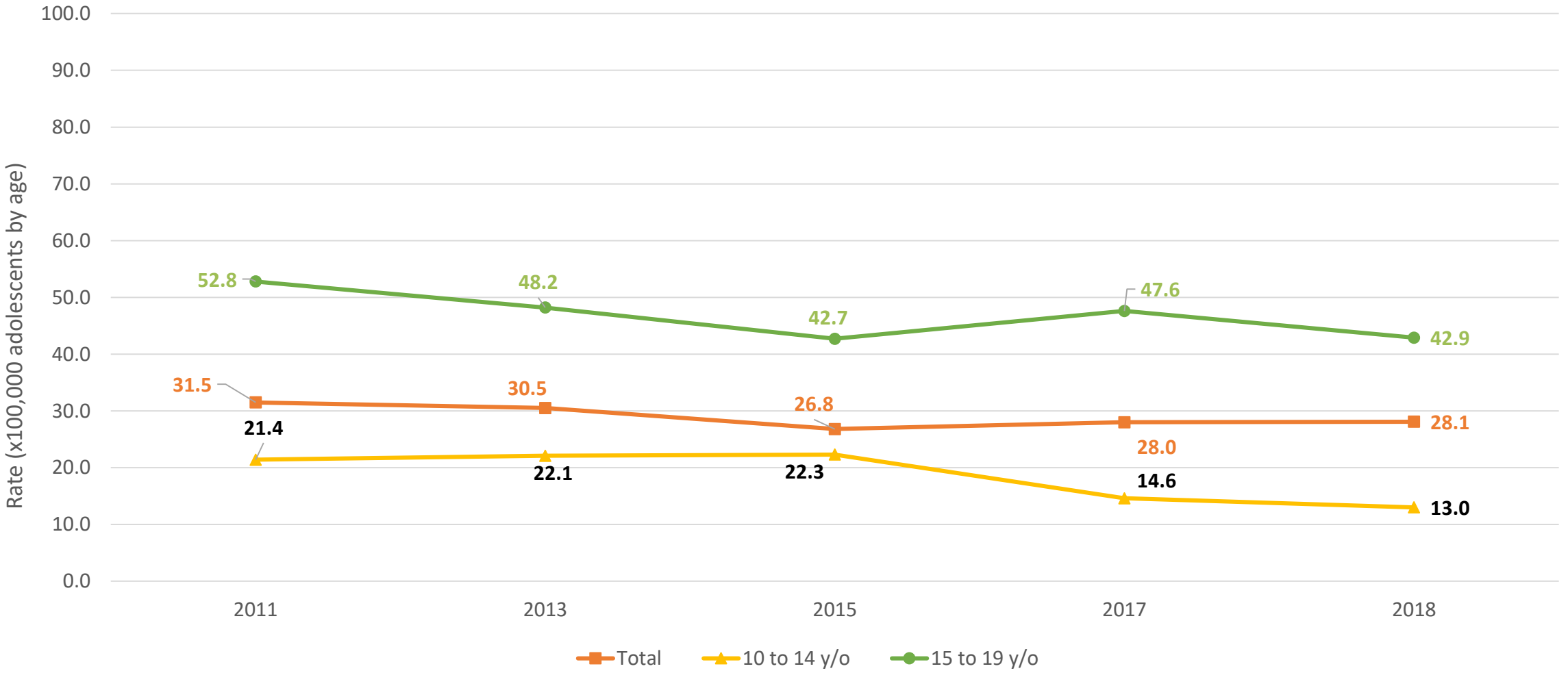
Figure 62: Current and lifetime asthma prevalence by age group Puerto Rico: 2015 to 2017



Source: Asthma Burden Report, PR Asthma Program de Puerto Rico, PR-BRFSS, 2015-2017; PR Department of Health.

Adolescent Health

Figure 63: Adolescents mortality rate by age group
Puerto Rico: 2011 to 2017



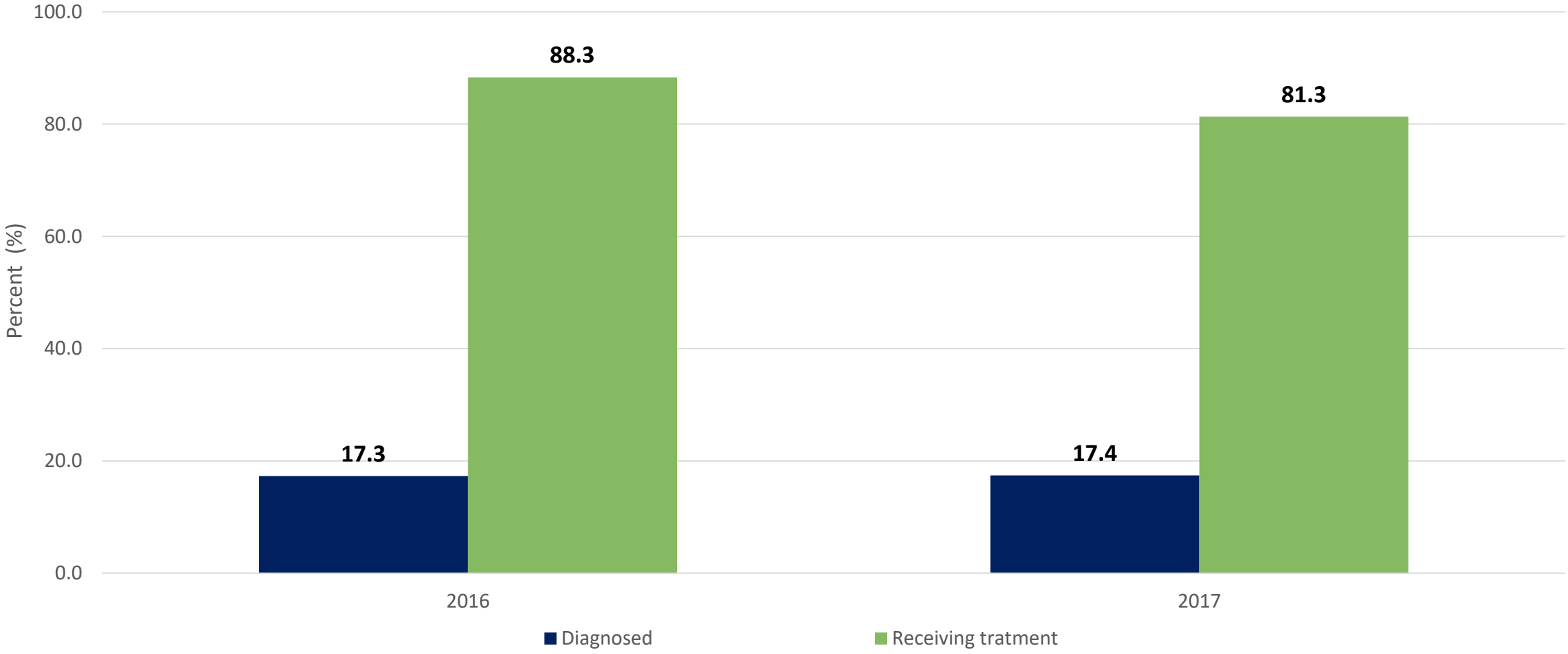
Source: PR-YRBSS, 9th to 12th grades, 2011 to 2017.

Figure 64: Leading causes of death in adolescents and young adults Puerto Rico: 2018

Rank	10-14 años	15-17 años	18-19 años	20-24 años
1	MV crash 2.7	Homicides 10.3	Homicides 10.3	Homicides 10.3
2	Unintetional injuries 2.1	MV crash 4.8	MV crash 11.8	MV crash 14.1
3	Suicides 1.1	Suicides 1.6	Unintetional injuries 3.5	Unintetional injuries 6.4
4	Diabetes 1.1	Unintetional injuries 0.8	Neoplasms 3.5	Suicides 3.7
5	Homicides 0.5	Heart disease 0.8	Suicides 1.2	Neoplasms 3.7

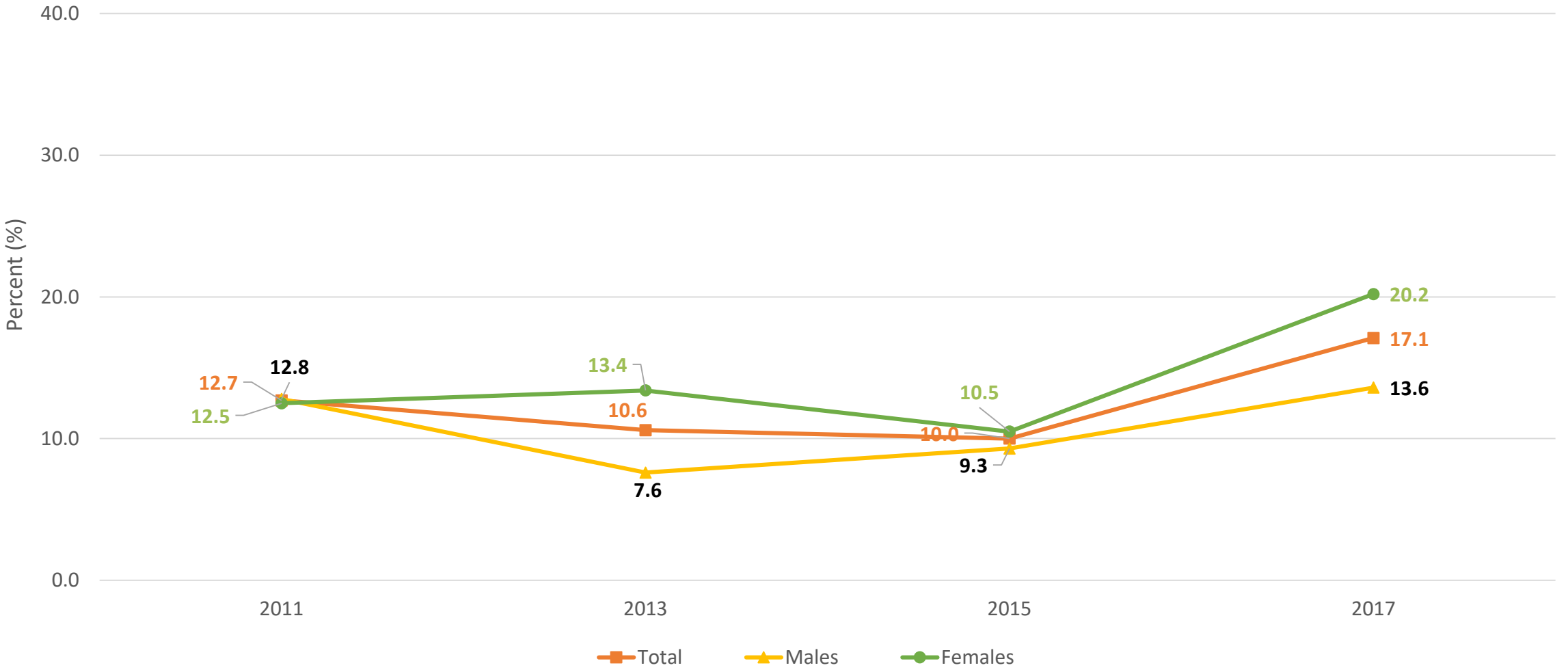
Source: Death Certificate 2018; PR Department of Health.

Figure 65: Adolescents 12 to 17 years old diagnosed with depression, anxiety or behavioral problems and received treatment Puerto Rico: 2016 & 2017



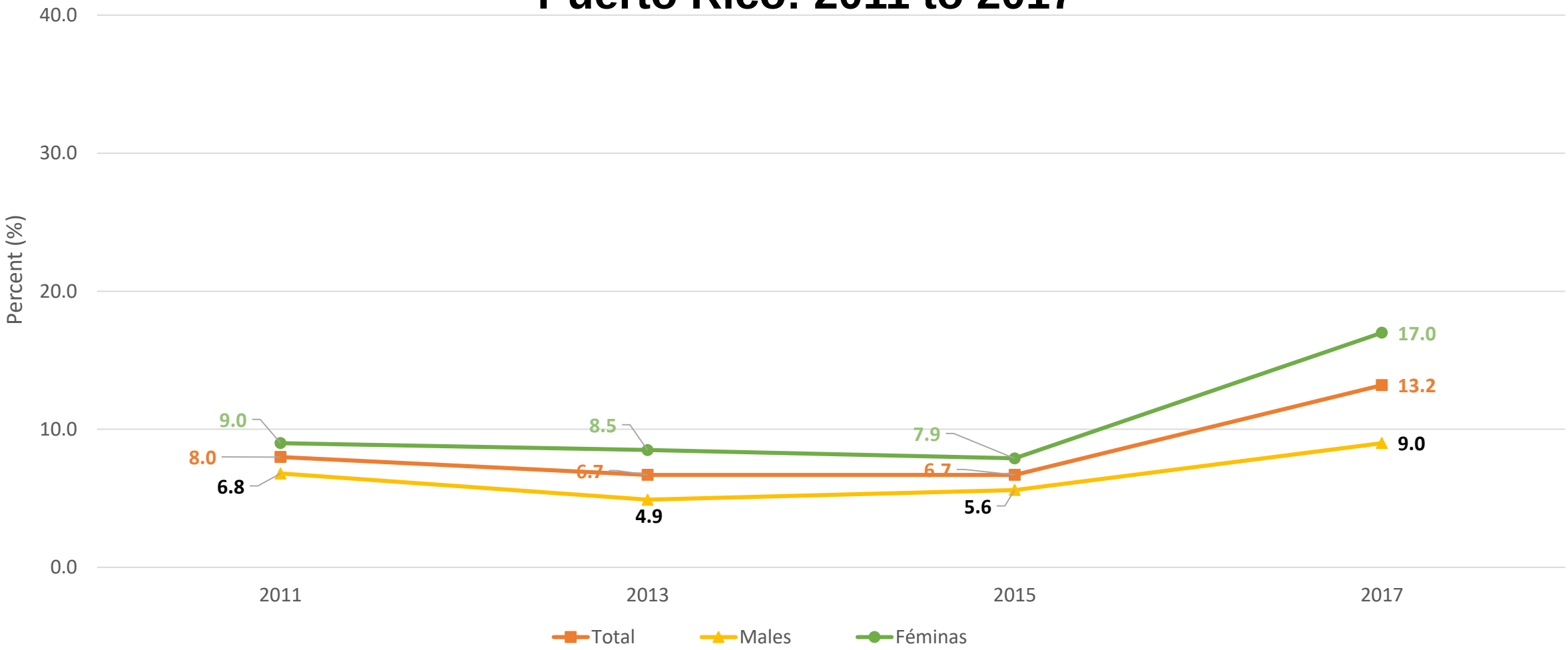
Source: PR-BRFSS, 2016 & 2017; PR Department of Health.

Figure 66: Adolescents from 9th to 12th grade that reported bullying at school by gender Puerto Rico: 2011 to 2017



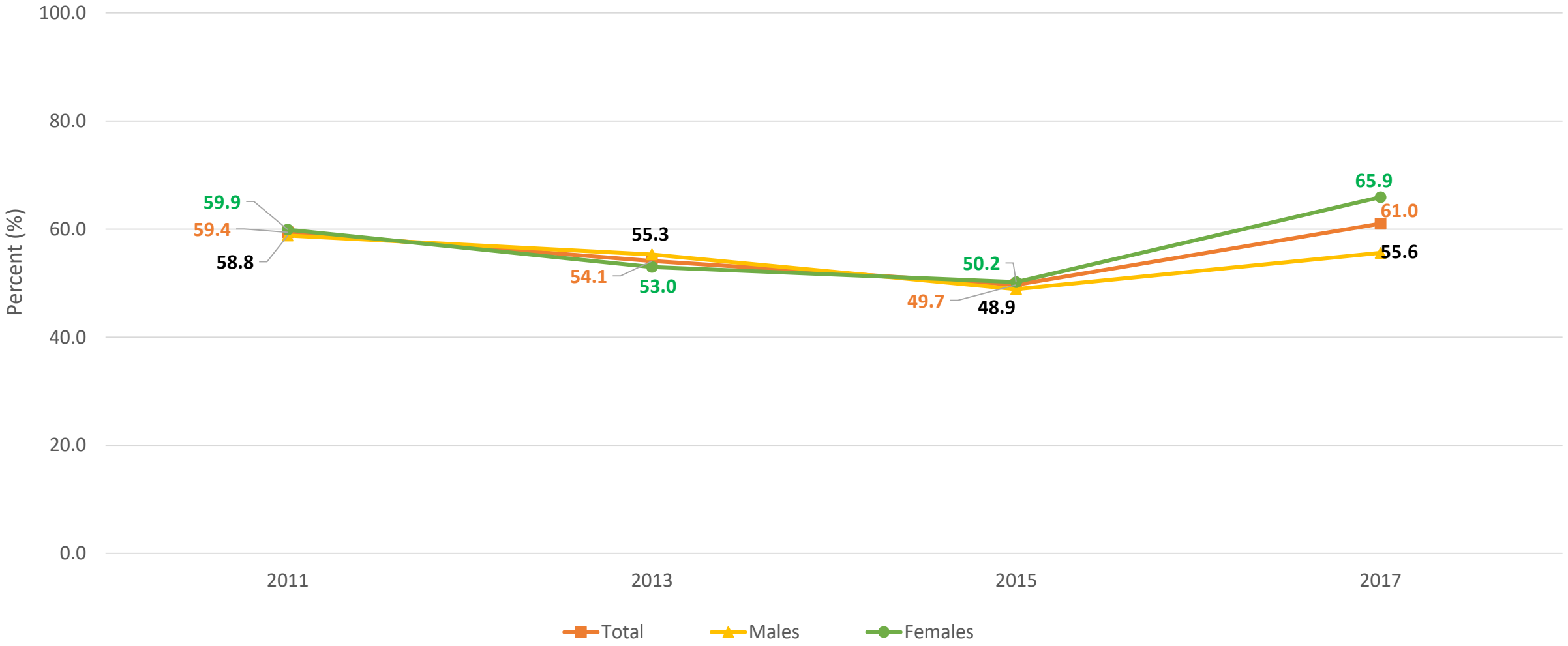
Source: PR-YRBSS, 9th to 12th grades, 2011 to 2017.

Figure 67: Adolescents from 9th to 12th grade that reported cyberbullying at school by gender Puerto Rico: 2011 to 2017



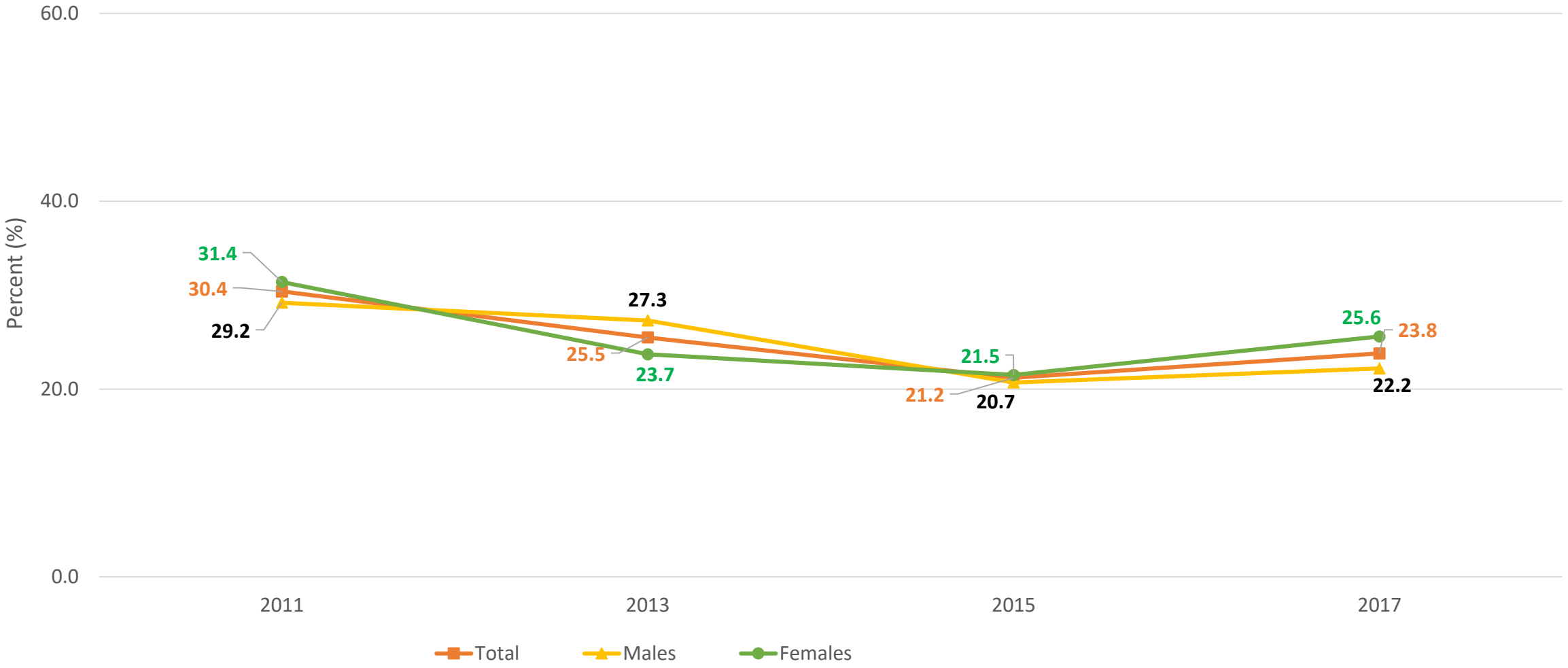
Source: PR-YRBSS, 9th to 12th grades, 2011 to 2017.

Figure 68: Adolescents from 9th to 12th grade that reported drinking alcohol at some time of their lives by gender Puerto Rico: 2011 to 2017



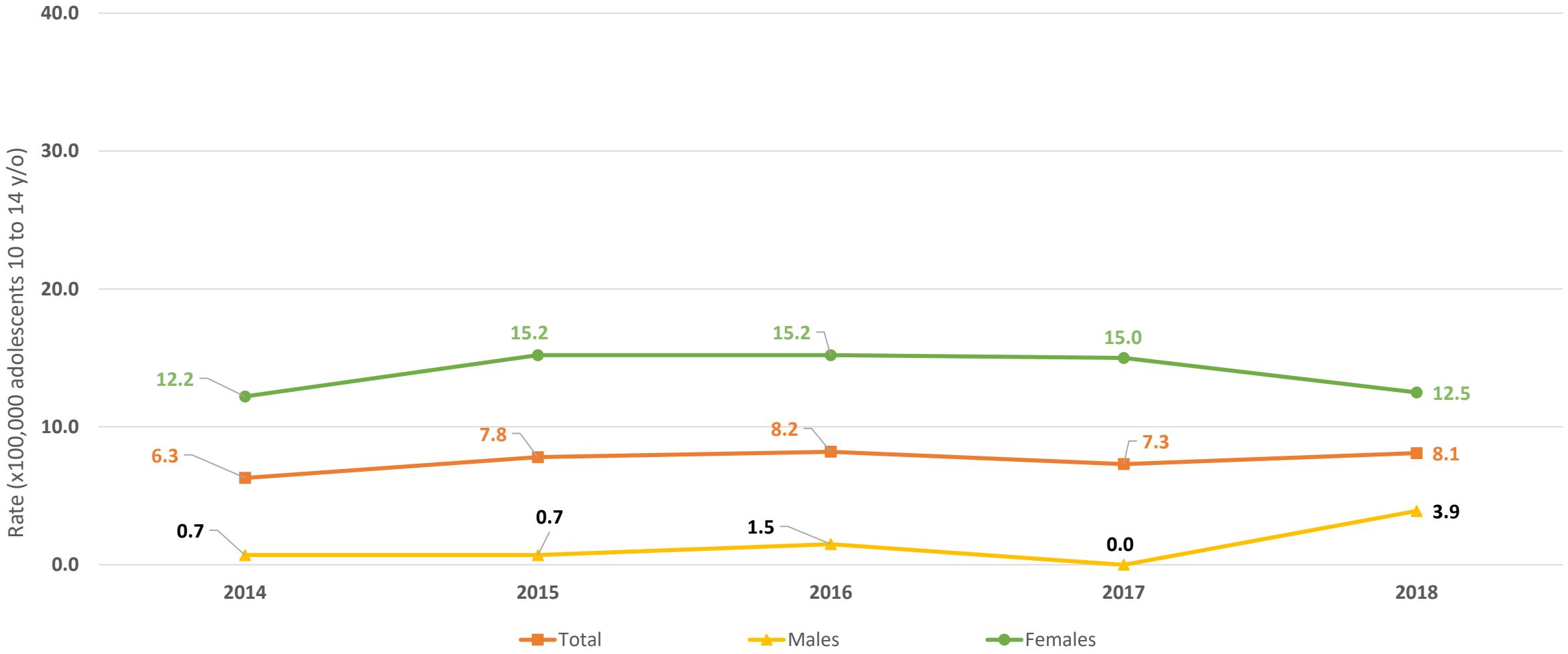
Source: PR-YRBSS, 9th to 12th grades, 2011 to 2017.

Figure 69: Adolescents from 9th to 12th grade that reported drinking alcohol during the last month by gender Puerto Rico: 2011 to 2017



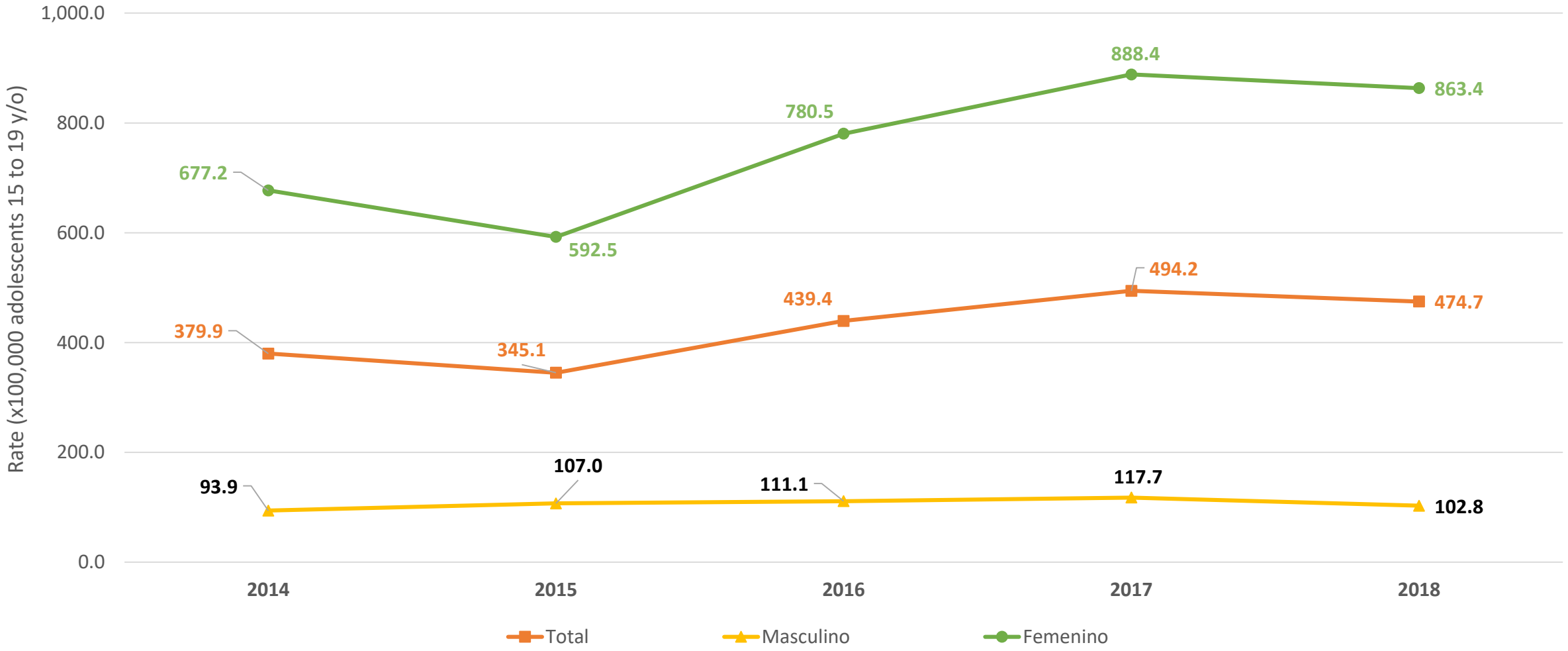
Source: PR-YRBSS, 9th to 12th grades, 2011 to 2017.

Figure 70: Chlamydia incidence rate in adolescents 10 to 14 years Puerto Rico: 2014 to 2018



Source: TSI/HIV/AIDS Program, 2014 to 2018. PR Department of Health.

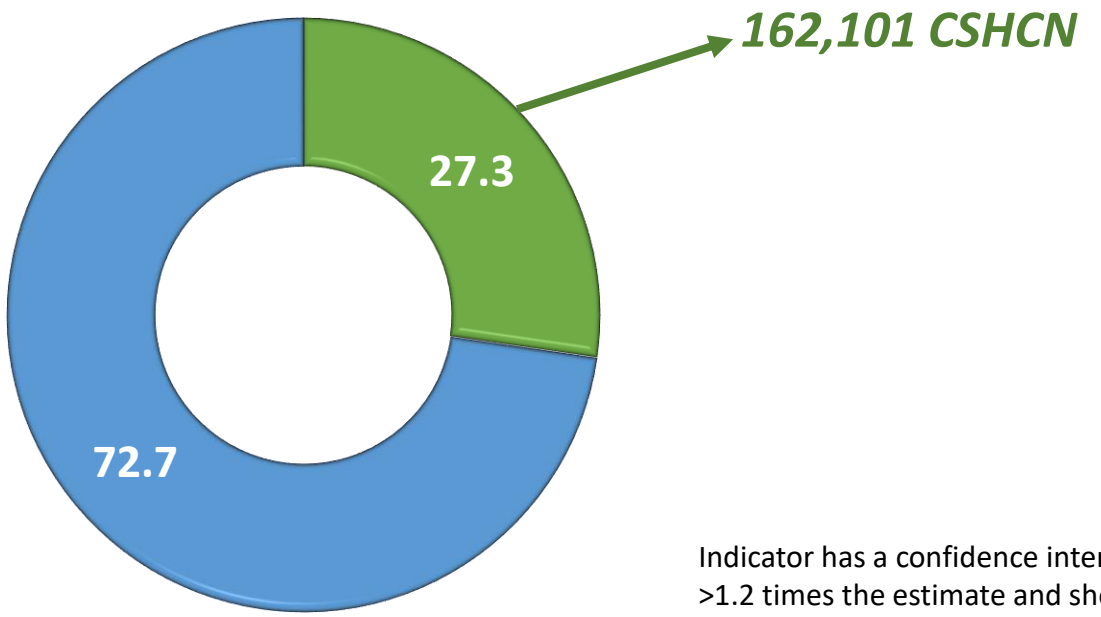
Figure 71: Chlamydia incidence rate in adolescents 15 to 19 years Puerto Rico: 2014 to 2018



Source: TSI/HIV/AIDS Program, 2014 to 2018. PR Department of Health.

Children with Special Health Care Needs

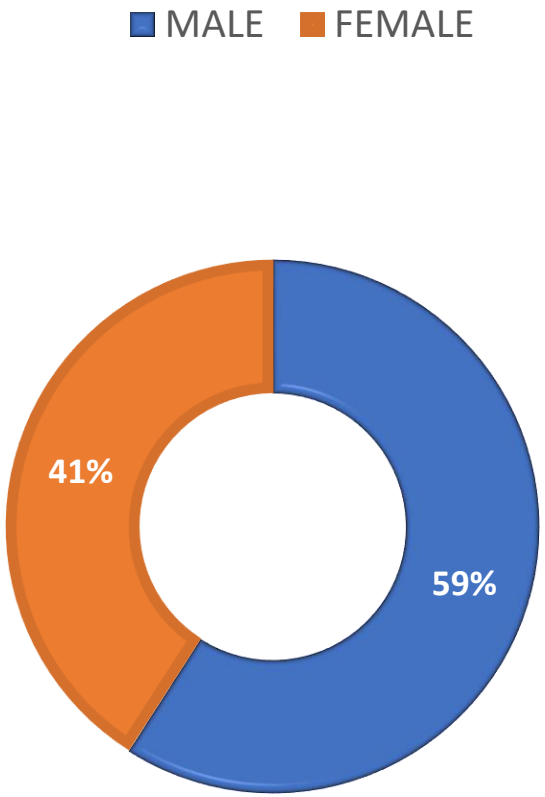
Figure 72: Prevalence of CSHCN 0 to 17 years of age
Puerto Rico: 2019

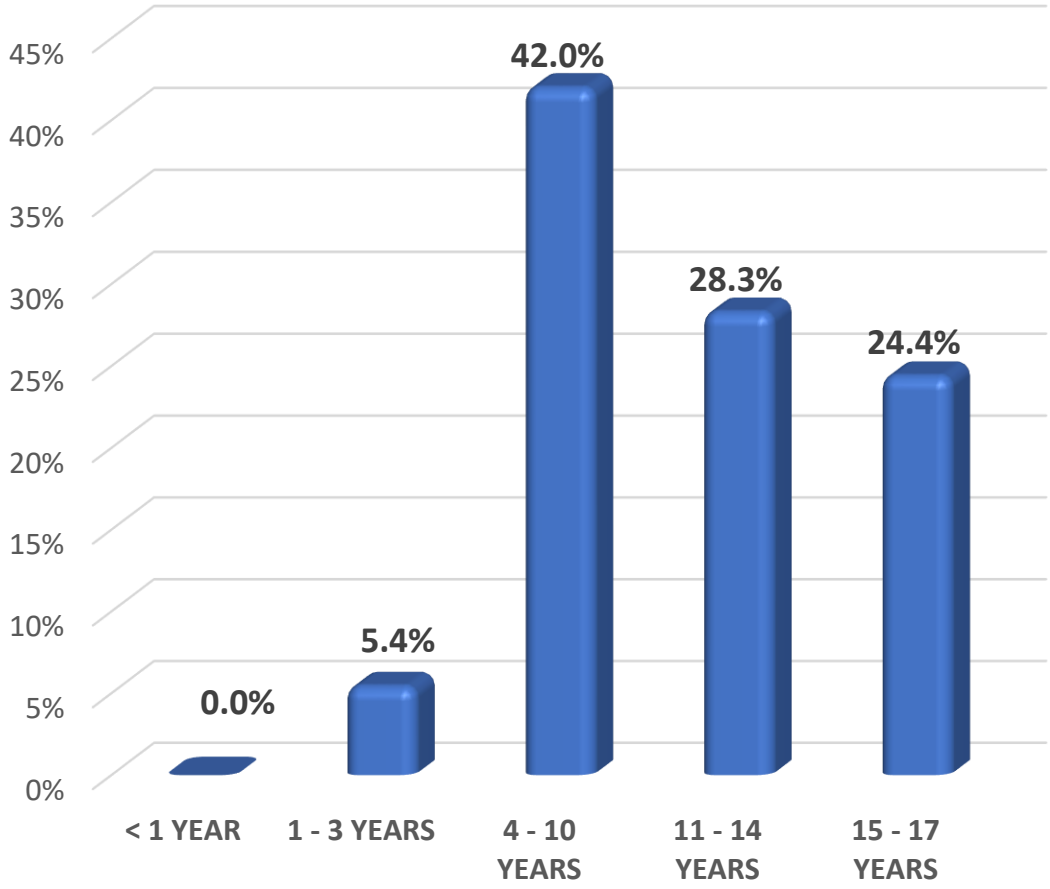


Indicator has a confidence interval width >20% or >1.2 times the estimate and should be interpreted with caution.

Source: 2019 MCH-JS Screener

Figure 73: CSHCN sex and age distribution
Puerto Rico: 2019





Source: 2019 MCH-JS Screener

Indicators have a confidence interval width >20% or >1.2 times the estimate and should be interpreted with caution

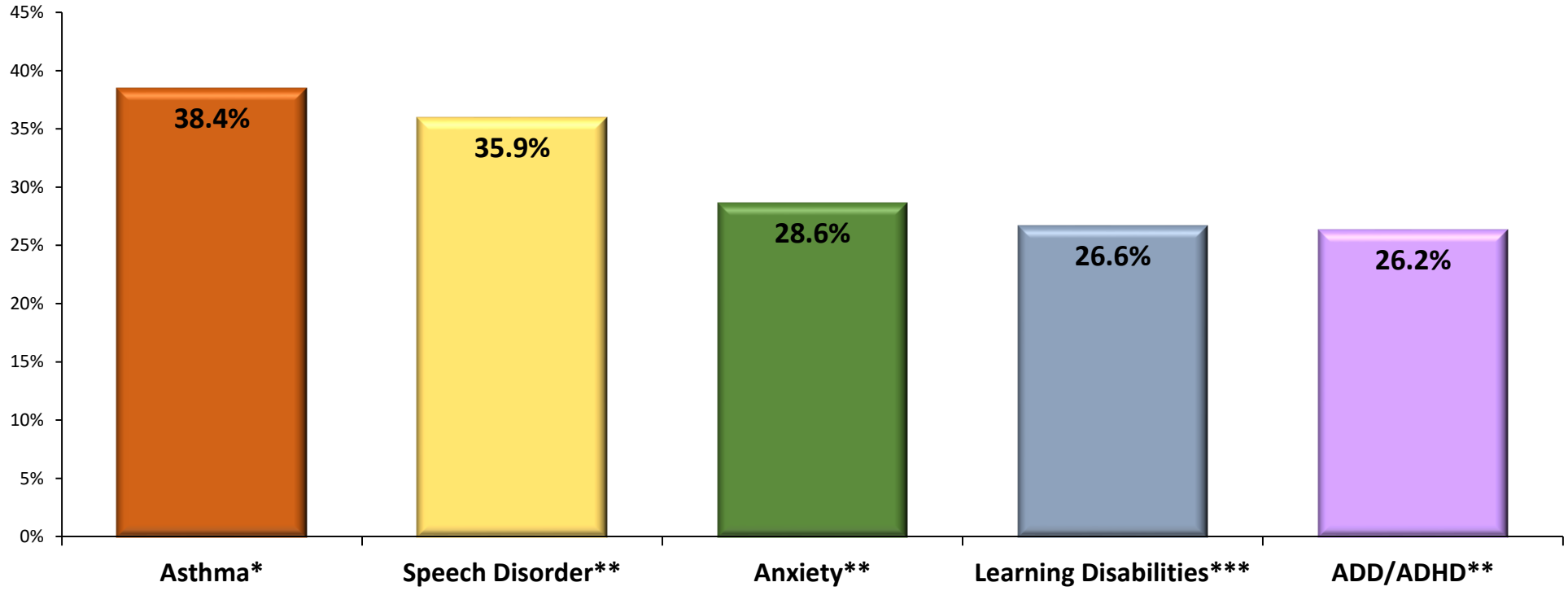
Figure 74: Prevalence of most frequent conditions in the CSHCN Population Puerto Rico: 2019

Rank	Conditions	Frequency	Prevalence
1	ASTHMA*	72,471	38.4%
2	SPEECH DISORDER**	67,167	35.9%
3	ANXIETY**	53,433	28.6%
4	LEARNING DISABILITIES***	49,044	26.6%
5	ADD/ADHD**	49,089	26.2%
6	BEHAVIORAL PROBLEMS**	41,387	22.1%
7	HEADACHES*	35,835	19.0%
8	DEVELOPMENTAL DELAY**	32,884	17.6%
9	DEPRESSION**	16,886	9.0%
10	AUTISM/ASD**	16,417	8.8%

Note: (*) ages 0-17 years; (**) ages 2-17 years; (***) 3-17 years

Source: 2019 MCH-JS. Difference in age ranges calculations are based on CAHMI, NSCH's Guide: (https://www.childhealthdata.org/learn-about-the-nsch/archive-prior-year-data-documents-and-resources/2011-12-nsch)

Figure 75: First five conditions in the CSHCN Population Puerto Rico: 2019

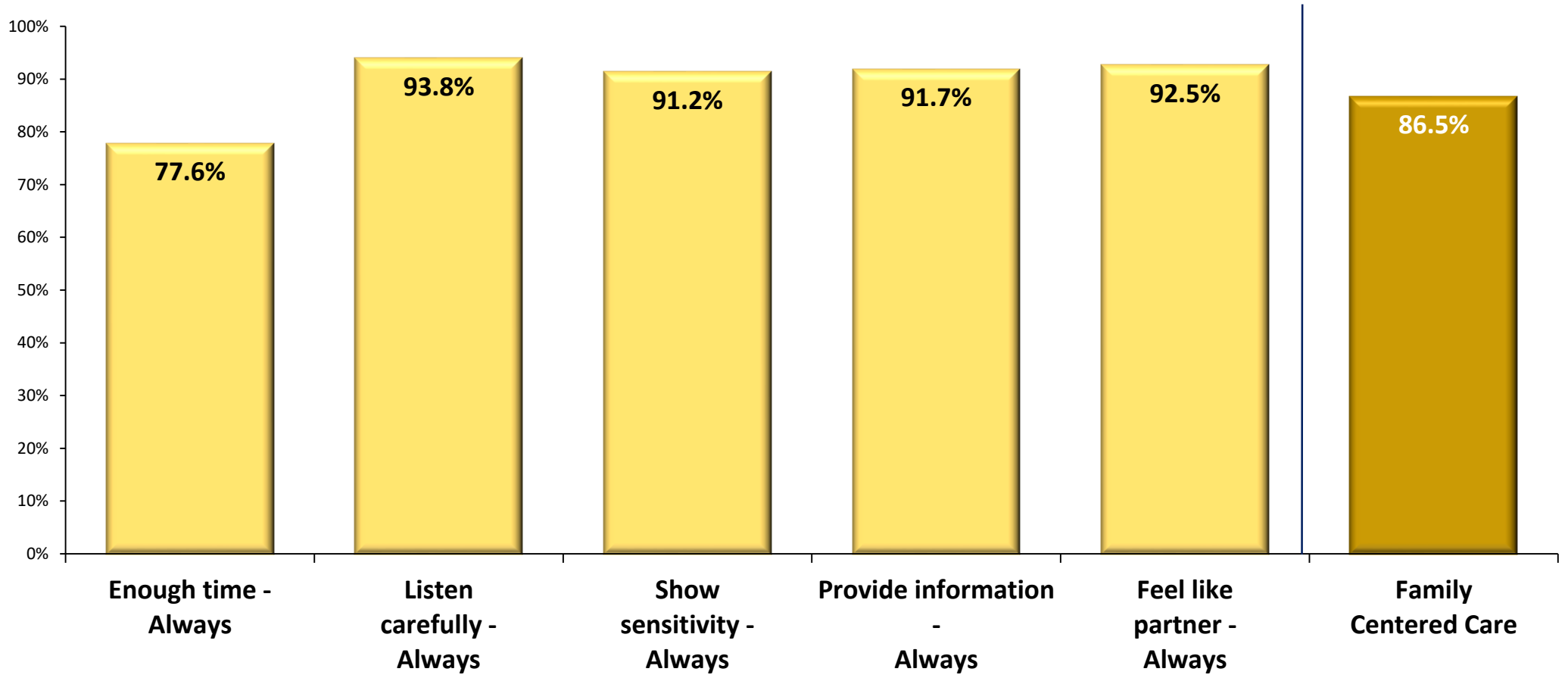


Note: (*) ages 0-17 years; (**) ages 2-17 years; (***) 3-17 years

Source: 2019 MCH-JS. Difference in age ranges calculations are based on CAHMI, NSCH's Guide: (https://www.childhealthdata.org/learn-about-the-nsch/archive-prior-year-data-documents-and-resources/2011-12-nsch)

Indicators have a confidence interval width >20% or >1.2 times the estimate and should be interpreted with caution

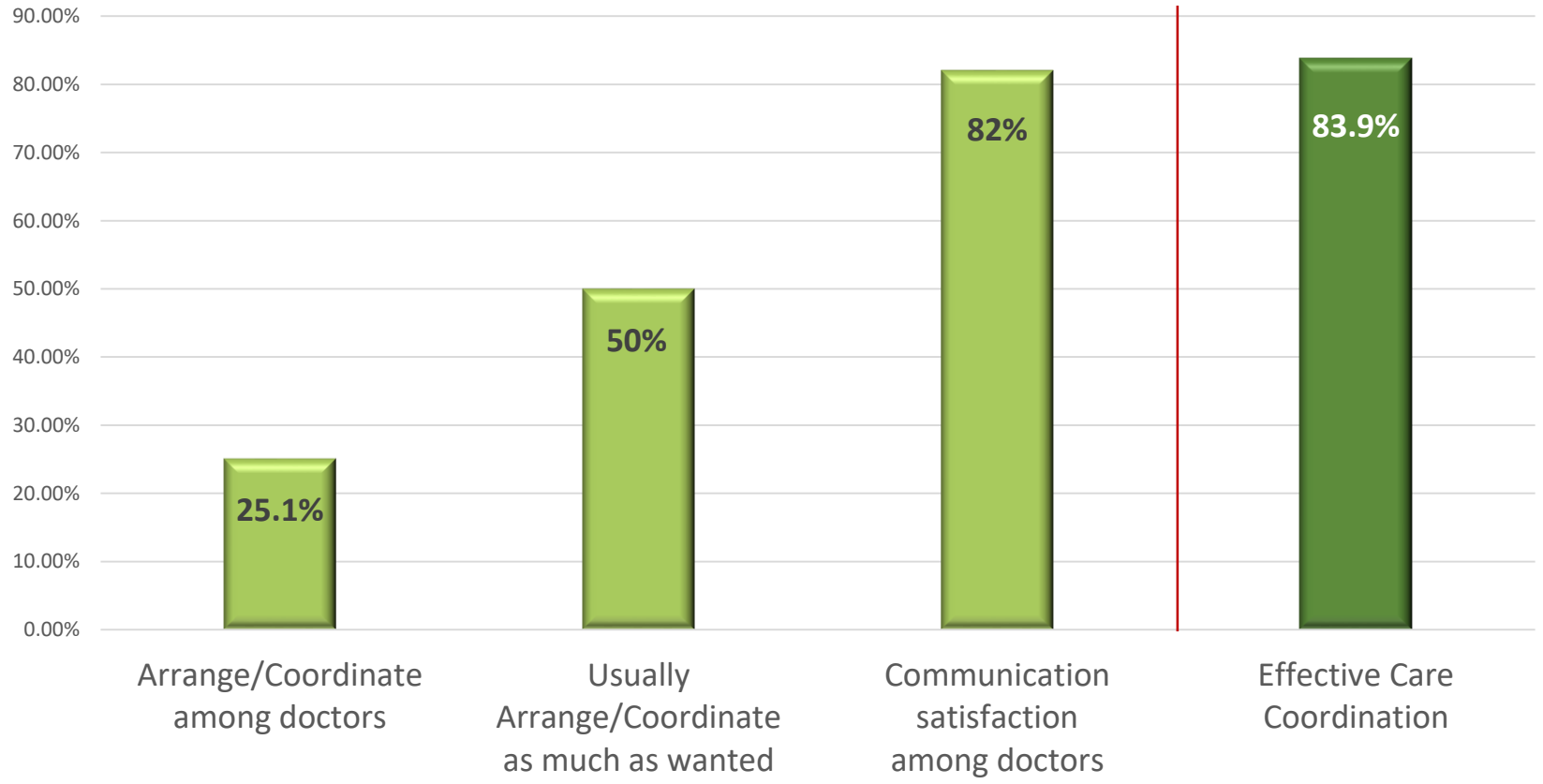
Figure 76: CSHCN Family Centered-Care
Puerto Rico: 2019



Source: 2019 MCH-JS

Indicators have a confidence interval width >20% or >1.2 times the estimate and should be interpreted with caution

Figure 77: Effective Care Coordination
Puerto Rico: 2019

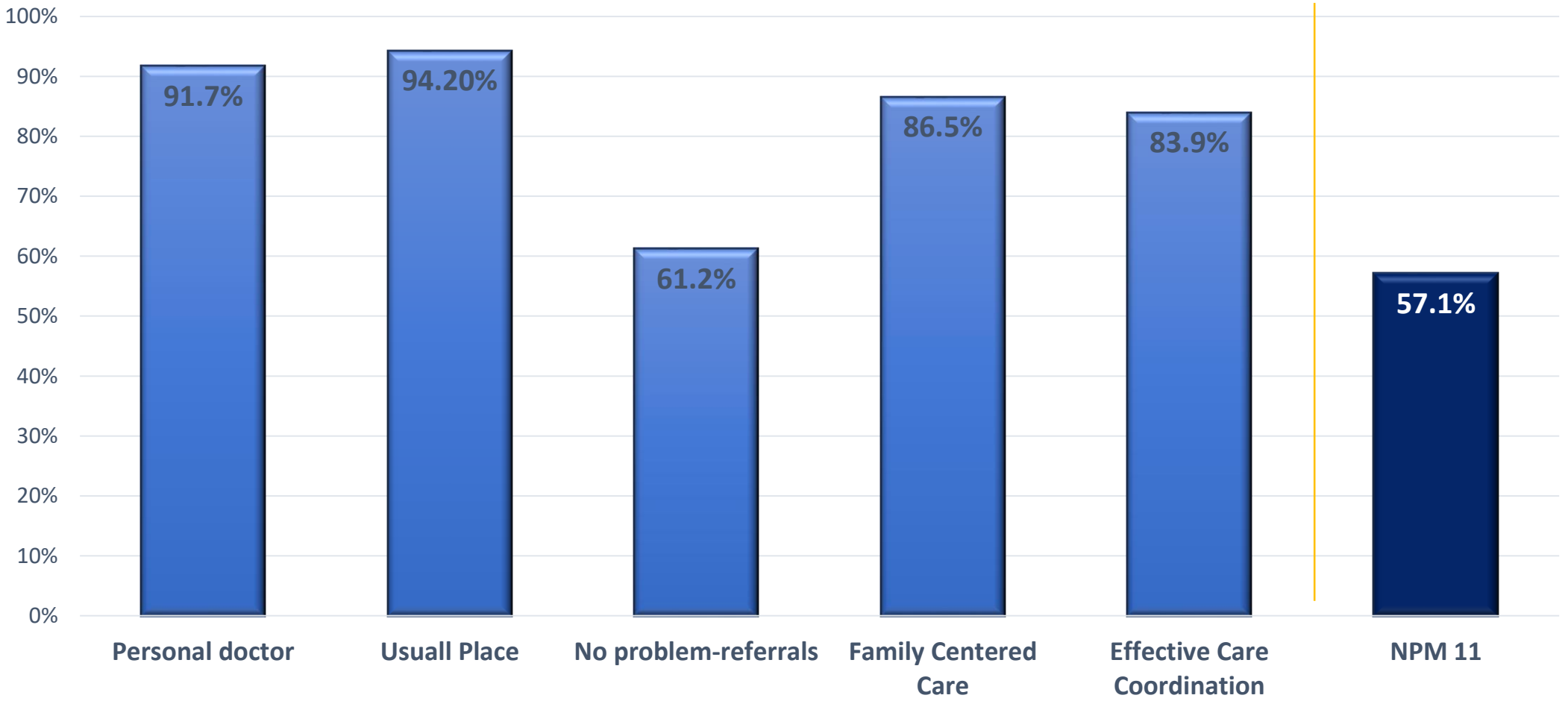


Source: 2019 MCH-JS

Indicators have a confidence interval width >20% or >1.2 times the estimate and should be interpreted with caution

Figure 78: NPM 11 - Medical Home for CSHCN

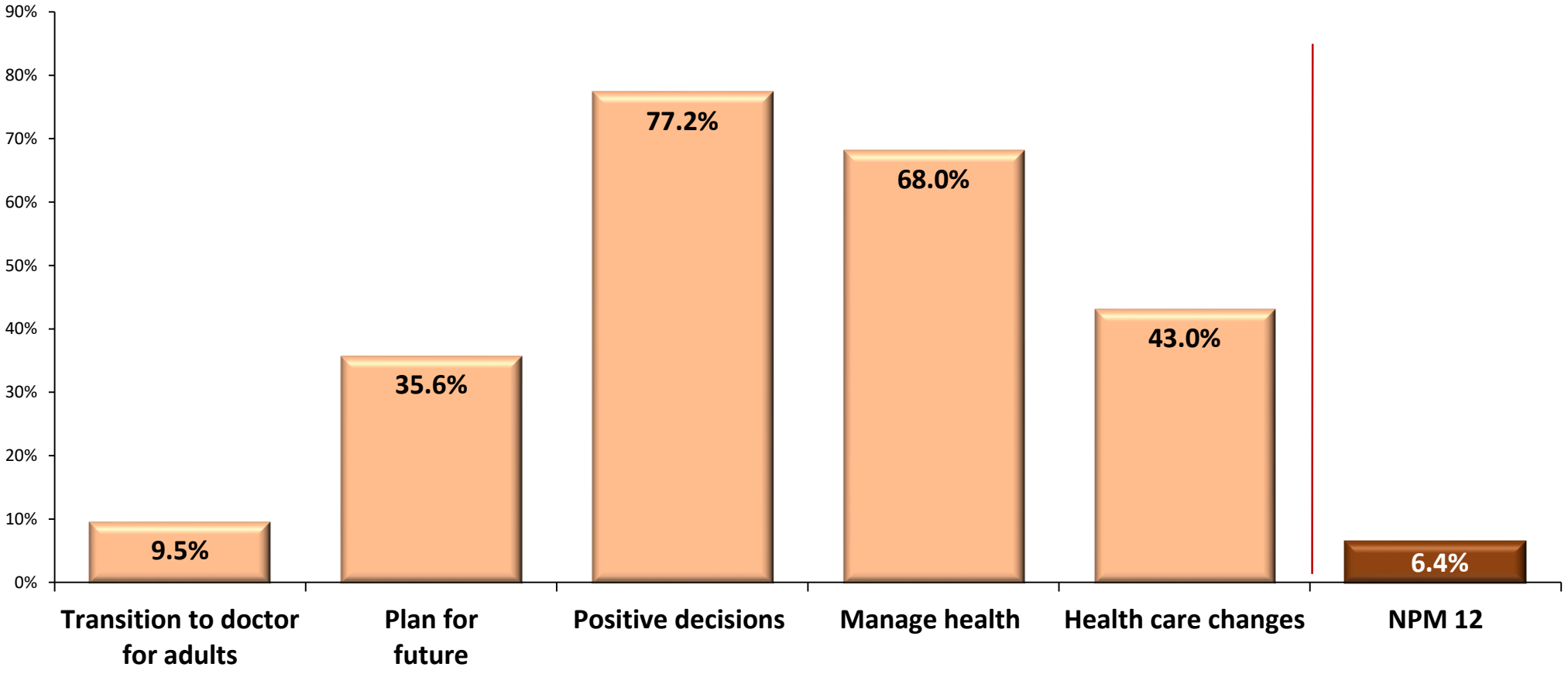
Puerto Rico: 2019



Source: 2019 MCH-JS

Indicators have a confidence interval width >20% or >1.2 times the estimate and should be interpreted with caution

Figure 79: NPM 12 - CSHCN transition to adult health care
Puerto Rico: 2019

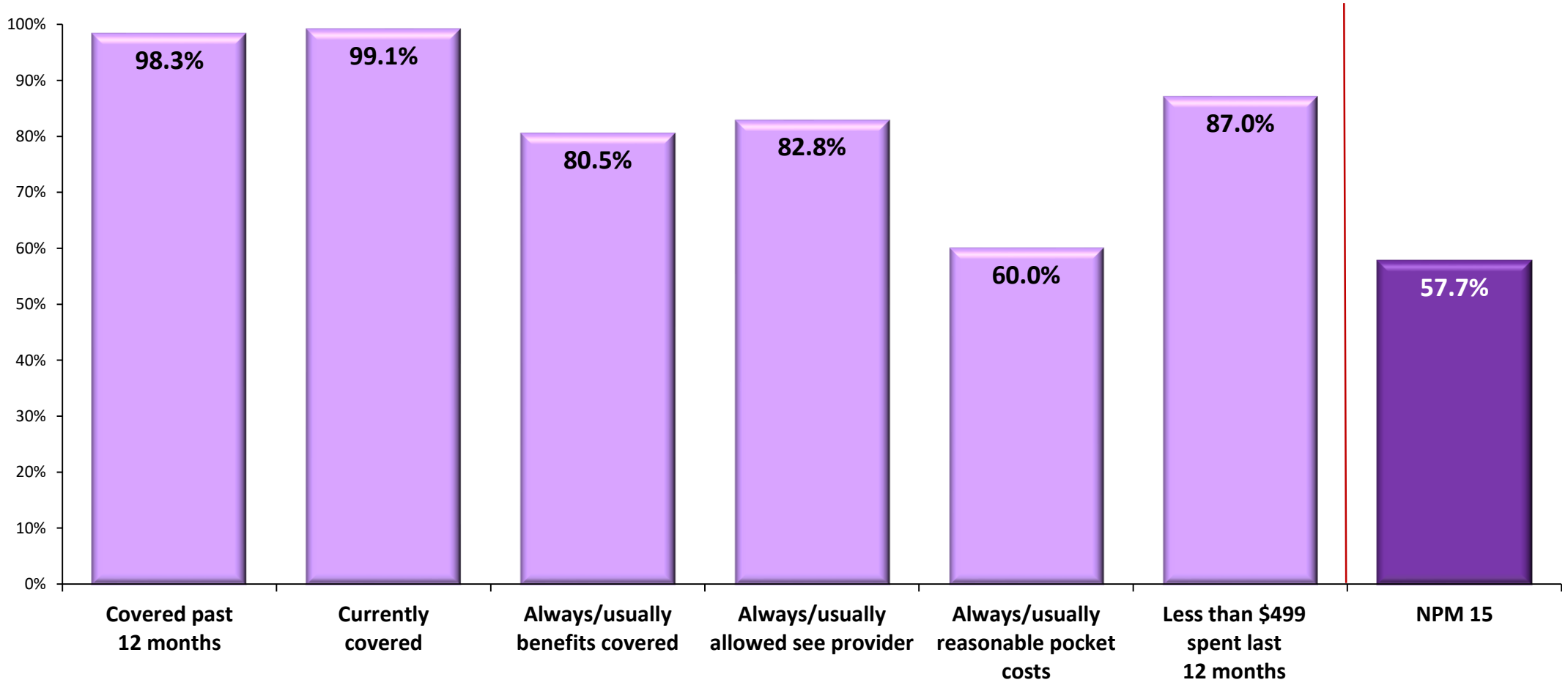


Source: 2019 MCH-JS

Indicators have a confidence interval width >20% or >1.2 times the estimate and should be interpreted with caution

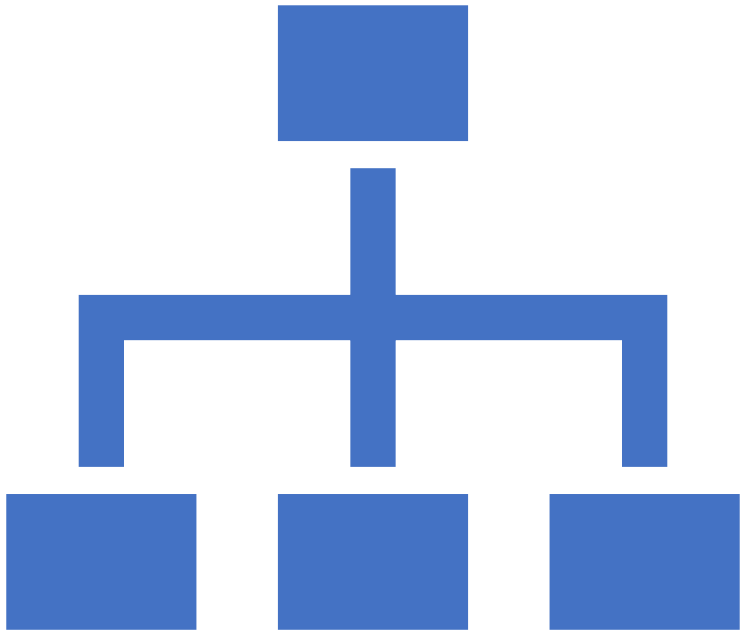
Figure 80: NPM 15 - Adequate insurance for CSHCN

Puerto Rico: 2019



Source: 2019 MCH-JS

Indicators have a confidence interval width >20% or >1.2 times the estimate and should be interpreted with caution



PR Title V

Organizational Structure