INTRODUCTION

Infant mortality has consequences for individuals, families, and society. Infant mortality is defined as the number of deaths to infants less than 1 year of age and is considered a sentinel indicator of a healthy society. Accordingly, reducing infant mortality and disparities in infant mortality are metrics by which we assess our progress toward improving population health and health equity.[1] Recent efforts in Maryland have contributed to declines in infant mortality from 7. in 2008-20012 to 6.5 in 2013-2017.[2] Nevertheless, Maryland's infant mortality rates remain higher than national rates, racial and regional disparities persist, and recent trends suggest an increase in infant mortality rates in rural areas of the state.

In 2018, the Maryland General Assembly passed a bill requiring the Maryland Health Care Commission (MHCC), on consultation with key entities within the Maryland Department of Health (MDH) and other stakeholders, to conduct a study on mortality rates for African American infants and infants in rural areas (2018 Md. Laws, Chap.83). Specifically, this study was designed to enable the General Assembly to understand the scope of infant mortality in Maryland, including its magnitude, how it varies across regions and racial and ethnic groups, and the availability of existing programs that address infant mortality in the state. Additionally, a detailed literature review on risk factors and effective programs for infant mortality was conducted. In keeping with these aims, the MHCC commissioned the University of Maryland, School of Public Health (MDSPH), Department of Family Science to conduct a study that would address several of these study aims.

This report summarizes information on existing programs that address infant mortality or its risk factors in the state of Maryland. We conducted a multi-pronged study in order to inventory existing programs and extract available information on each program using publically available information (i.e., websites and online program documents), and to implement a targeted survey. The survey was designed to supplement the web searches to collect more detailed information on program effectiveness and constraints, such as best practices and challenges for sustaining effective programs.

[1]Braveman PA, Kumanyika S, Fielding J, Laveist T, Borrell LN, Manderscheid R, Troutman A. Health disparities and health equity: the issue is justice. Am J Public Health. 2011 Dec;101 Suppl 1:S149-55.

[2]https://health.maryland.gov/vsa/Documents/Reports%20and%20Data/Infant%20Mortality/Infant_Mortality_Report_2017_20180919.pdf

CHARGE: INVENTORY OF STATE PROGRAMS

The specific charge for this component of the study was to conduct a comprehensive inventory of Maryland's local and state programs focused on infant mortality in collaboration with state staff, the advisory work group and subgroups. For this purpose, we defined a program with a focus on infant mortality as one that addresses infant mortality, specific causes of infant mortality (e.g., low birthweight, sudden infant death syndrome), or its risk factors (e.g., teen pregnancy, birth spacing). The strategies applied were designed to be inclusive of all identified state, local, and nonprofit organizations, rather than specific to a few programs, and be updated iteratively.

METHODOLOGY

Inclusion criteria

Programs were included if they directly addressed infant mortality, its causes, or its risk factors. We further refined the inclusion criteria to only include programs that had an explicit focus on the periods that could affect pregnancy and infant health (i.e., preconception, prenatal, or postpartum period). For example, programs in Maryland have been developed to address substance abuse (a risk factor for infant mortality); however, one program specifically identified pregnant women as a target population of their program and was included in the inventory list. This inclusion ensures that the mission of each program is consistent with the broader aims of the MHCC study.

Search strategy

A list of programs was generated using documents on state-funded programs available through MHCC and MDSPH staff. To supplement this list, targeted web searches using Google search engine were also conducted. The following search strategy was recommended by the University of Maryland Public Health Librarian: ["Subject Term" program Maryland site:.org] or ["Subject Term" intervention Maryland site:.org]. The subject terms included "infant mortality," "birth outcomes," "preterm birth," and "low birthweight." Sites also included .gov and .edu extensions. Programs were added iteratively if they were identified during review of data sources. A question was also included in the survey that queried respondents on any additional programs related to infant mortality or its risk factors in the state.

An initial contact sheet was developed based on documents and searches (Appendix A). This contact sheet includes the specified websites, links to program documents, and contact

information. If available, contact information of a program director or related position was also collected.

Data sources

Information on identified programs was obtained from two sources: 1) publically-available information from websites and online program documents and 2) a detailed survey developed in Qualtrics (see Appendix B). The survey component of this study received MDSPH Institutional Review Board (IRB) approval.

Data collection

Information was extracted from websites or a survey based on criteria specified within the Interagency Agreement between MHCC and MDSPH. This included information on the type of organization, names of programs, duration of the programs, types of services offered, demographics and geographic areas of individuals within the program, program costs, funding sources and sustainability of the program, program evaluations and, if available, effectiveness of short and long-term outcomes, and best practices and challenges related to sustainability (see Appendix C for extraction sheet). Specifically, the agreement included:

- Type of program (home visiting, peer support, etc.). A checkbox list of known types of programs will be entered with an open-ended option to list other program types.
- Types of services offered within the program that address infant mortality or its related risk factors.
- Provider types involved in the program. This may include programs that are using pregnancy navigators and community health workers for pregnant women.
- The frequency and duration of the program components (i.e., when and how often services were provided).
- Entity that runs and manages the program.
- The number of individuals served and the target population of the program. If available, additional details will be collected on the demographics of individuals served, how the program reaches individuals, and who the program may not be reaching.
- The geographic area served within the state.
- Program costs (total and per capita) if available.
- Funding source and sustainability of the program.

- If available, evaluation and effectiveness information and information on best practices, challenges, and approaches to enhance cost savings. Specifically, impact on African American infants, rural infants, and overall outcomes (e.g., mortality, birthweight, preterm birth).

Information was collected differently depending on the data source. For the publically-available information, undergraduate and graduate research assistants reviewed websites and key program documents. Information that fit each criterion were populated using a Google spreadsheet. Information that was not available for a specific criterion was marked as unavailable, unclear, or left blank. Additional notes were collected in cases where content may be relevant, but did not meet a specific criterion in the extraction table (Appendix C).

The survey was emailed to identified contacts with an invitation and link to participate in this study. Programs that had not responded to the initial email were sent an additional reminder. A follow-up phone call was made for the third attempt. After the third attempt, the program was no longer contacted and this information was documented on the tracking sheet. *[In progress]*

Analysis

Web extraction

Extracted information from publically-available data sources was reviewed and summarized. The web extraction was used to examine 5 main questions:

- *What programs exist that address infant mortality or its risk factors in the state?*
- *What types of services are available within these programs?*
- *To what extent do these services address or have the potential to address specific risk factors in the population?*
- *How are these programs distributed in Maryland?*
- *What additional innovative approaches are used to support programs and their clients' needs?*

Programs were divided into state, county, and non-profit or other types of programs. Details from the web extraction were further categorized into the types of services covered, populations targeted, and geographic (county-level) distribution. The summary statistic was based on the percent of programs that mentioned a particular type of service or population (i.e., density of each type of service, population served). The denominator for types of services covered was 81 total programs. The denominator for populations targeted and geographic distribution was 71

total programs, which excludes the 10 programs that focus on data collection or review and recommendations rather than service delivery.

The types of services were also sorted by the extent to which programs addressed clinical, behavioral, and social risk factors (Causal Diagram for Infant Mortality and Related Outcomes, David Mann). This was determined based on whether a service or combined set of services could address a particular risk factor. The level of coverage was divided based on their density (summary statistic) into High (30% of programs or greater), Moderate (10-29.9%), and Low (< 10% of programs) coverage. The geographic distribution of programs within counties was also contrasted with the population density in the county (*to be replaced with number of live births*) and each county's infant mortality rate. Finally, innovative approaches that encouraged greater outreach within the community and supplementary services that would support further sustainability or reach of the program were also noted.

Survey - [In progress]

FINDINGS - WEB EXTRACTION

What programs exist that address infant mortality or its risk factors in the state?

Overall, we identified a total of 81 programs in the state. Twenty-six programs (32.1%) were part of Maryland government initiatives (Table 1). Of these state programs, the majority (n=23) were part of the Maryland Department of Health, 2 programs through the Department of Human Services, and 1 program through the Department of Education. Thirty-one county health department programs (38.3%) were identified. Some programs were unique to a specific county (e.g., Center 4 Clean Start) and some were found across several counties (e.g., Healthy Families; Family Planning). Additionally, 24 non-profit or other types of programs were identified, some of which included grantees from the Maryland Community Health Resource Commission (https://health.maryland.gov/mchrc/Pages/home.aspx). Ten programs were identified as providing data collection, review, oversight, or recommendations, but not direct services in the state. Examples of these programs include Pregnancy Risk Assessment Monitoring System (PRAMS), Fetal and Infant Mortality Review (FIMR), Maternal Mortality Review Committee (MMRC), Birth Defects Reporting and Information System, Maryland Patient Safety Center, Perinatal Systems Standards, Title V Block Grant, Maryland Institute for Emergency Medical Services System, Child Fatality Review, and Maryland Hospital Breastfeeding Policy Recommendations.

Table 1. Programs to address infant mortality or its risk factors in Maryland identified by web search criteria, by type of organization

Organization type	Number	%
Government agency - state	26	32.1
Government agency - county	31	38.3
Non-profit/Other	24	29.6
Total	81 programs	100
Total (excluding data collection or review/recommendation programs)	71 programs	87.7

What types of services are available within these programs?

The most prevalent types of services mentioned on program websites were home visiting (42.0%), health education services (44.4%), and referral services (45.7%) (Table 2). These services were specific to the type of program and needs of their clients. For example, home visiting may address child development screenings, substance abuse, provide some prenatal care, or address other factors in the home. Similarly, programs that offer referral services may provide linkage to substance abuse programs or identify women with specific health conditions during pregnancy and refer them to high-risk care. In terms of direct health care services, a number of programs provided prenatal (individual or group) (16.0%) and reproductive health/family planning services (18.5%). Social support services were also mentioned more frequently and included peer/family support or counseling (19.8%) and pregnancy support and navigation, including doula services (16.0%). Data collection, review, or recommendations was a key service of 12.3% of programs identified. Less than 10% of programs explicitly mentioned safe sleep (4.9%), teen pregnancy prevention (7.4%), smoking cessation (4.9%), substance abuse (9.9%), mental health services (4.9%), housing (3.7%), breastfeeding support (8.6%), and nutrition support (7.4%).

Table 2. The percentage of infant mortality programs in Maryland that mention offering specific types of services based on review of websites and program documents

Type of service offered	Number	%
Home visiting	34	42.0%
Peer (and family) support, counseling	16	19.8%
Safe Sleep	4	4.9%
Health Education (e.g., parenting classes, sex education, baby care kit, prenatal classes)	36	44.4%
Teen Pregnancy Prevention (or Teen Parent support)	6	7.4%
Smoking Cessation (screening and/or services)	4	4.9%
Substance Abuse (screening and/or counseling) (or Plan of Safe Care for Infants)	8	9.9%
Mental health services*	4	4.9%
Family planning, women's/reproductive health care (e.g., STD screening/treatment)*	15	18.5%
Housing (e.g., transitional housing, home safety classes)	3	3.7%
Breastfeeding support (not education)	7	8.6%
Nutrition support (not education) (e.g., meal prep, planning)	6	7.4%
General prenatal care only	10	12.3%
Group prenatal care (if group care, often also provide individual)	3	3.7%
Referral services (behavioral health, substance abuse, pregnancy care, care coordination, case management, service linkage, etc.)	37	45.7%
Pregnancy support and navigation (including doula services, pregnancy kits, birth plan)	13	16.0%
Data collection, evidence review (PRAMS, FIMR, MMRC, Birth Defects, MD Patient Safety, Perinatal System Standards; Title V Block Grant reporting, MIEMSS Perinatal, Child Fatality Review)	10	12.3%
Other**	29	35.8%

*option not on survey; ** transportation services, assistance in obtaining insurance or WIC, mother-infant care, primary care, father child program, language or deaf/blind services, policy/advocacy, child development screening, car seat safety, on-site childcare, Safe Haven, GED and adult education, errand support, resources to encourage reading to child

To what extent do these services address or have the potential to address specific risk factors in the population?

Using the percentage of infant mortality programs that mention specific types of services, we mapped this information by whether or not the types of services could address specific risk factors for infant mortality and the extent to which they were mentioned/offered from the identified programs (Table 3). Clinical and behavioral risk factors are the most proximal determinants to address disparities in infant mortality. Clinical risk factors showed low to moderate coverage based on review of publically-available information. Specifically, reproductive health services and family planning could prevent sexually transmitted infections, short birth spacing, and teen pregnancy (Moderate coverage). Other health factors and behaviors, such as diabetes, hypertension, nutrition, psychosocial risks (depression, anxiety), substance abuse, and smoking were less likely to be mentioned directly (Low coverage).

However, referral services, care coordination, or home visiting services may be addressing these risk factors or have the opportunity to more explicitly address these factors.

Socioeconomic and access-related risk factors varied in terms of coverage. There was a high level of coverage for access to care if we combined programs offering prenatal care and reproductive health care services, which has the potential to address preconception and prenatal health. Additionally, home visiting services provide an opportunity to extend care into the postpartum period. A number of services are designed to increase education on parenting, infant care, and safe sleep practices (high coverage). Additionally, social support could be enhanced through services that offer peer networks, group prenatal care, family counseling and pregnancy navigation. These services had moderate to high coverage. Finally, there was limited mention of programs that address insurance access (unless through referral or care coordination), neighborhood factors, resources and income to support improved preconception, prenatal, and infant care, and racism; the latter of which could be addressed through expanding on existing programs that use community health workers, doulas, pregnancy navigators, and enabling services, such as language interpreters.

Table 3. Risk factors for infant mortality by the extent to which these services are provided in Maryland based on review of websites and program documents

Risk factors	Density of services to address risk factor
Risk factor - Clinical	
- Short birth spacing, young age at birth (family planning, teen pregnancy)	Moderate (FP, teen pregnancy prevention)
- Sexually transmitted infections	Moderate (women's health services)
- Other health factors (diabetes, hypertension, nutrition)	Low – nutrition (mainly through WIC) Moderate/High – prenatal care, primary care, pregnancy support
- Psychosocial risks (e.g., depression, anxiety)	Low – mental health services, but opportunities may exist within existing programs (e.g., home visiting)
Risk factor - Behavioral	
- Substance use/abuse	Low – substance abuse (not including referral services)
- Smoking	Low, but opportunities may exist within existing programs
- Access to care (primary, reproductive, prenatal, postpartum)	High (home visiting, prenatal care, reproductive, primary)
- Insurance	Low/Moderate (portion within programs)
- Social support (e.g., partner, family, IPV)	Moderate/High (peer support, pregnancy navigation, group PNC, limited mention of IPV but could be due to our inclusion criteria)
- Education (e.g., safe sleep environment, infant care)	High!
- Resources, income (to provide care, safe environment, breastfeeding, etc.)	Low (crib provision minimal, breastfeeding support/equipment, housing environment safety provisions)
- Neighborhood factors (e.g., housing, unsafe environment, transportation)	Low (Few safe sleep programs, safe housing/neighborhood not addressed, transport services mentioned in a few programs)
- Racism	Low (could be integrated within existing programs through CHWs, doulas, pregnancy navigators, language interpreters)

How are these programs distributed in Maryland?

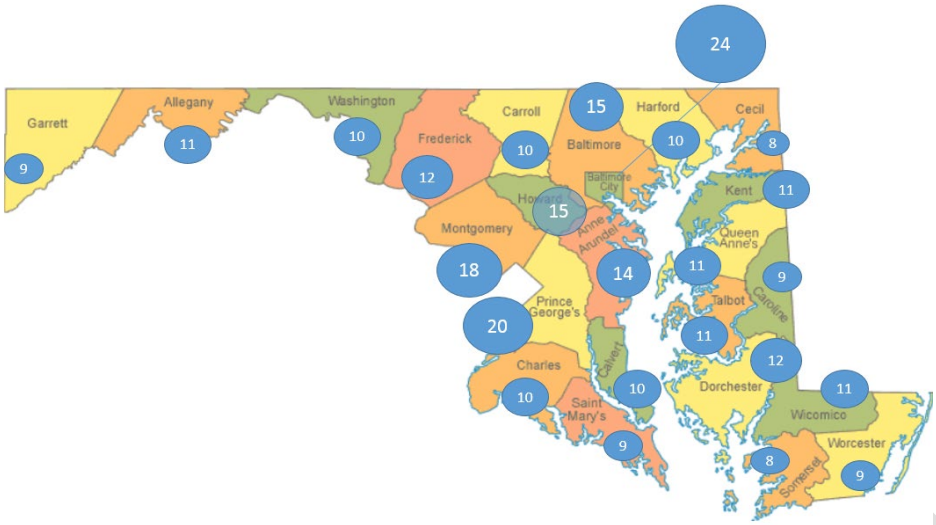
Of the programs that provide direct services to the Maryland population (71 programs), we found that the websites or documents mention that they only serve or serve a large majority of low-income individuals, including un- or underinsured individuals (40.8%) (Table 4). The identified programs are mainly targeting pregnant women (42.2%), infants/children (19.7%), or non-pregnant mothers (29.6%), the latter of which could include parents of teenagers. Fewer programs mentioned the father or family specifically (11.6%). About 12.7% of programs mention serving specifically racial/ethnic minorities or marginalized populations and about half of all programs were in rural communities (50.7%).

Specifically, when we examine the geographic distribution of programs, we find the highest number of programs in the more populated counties (Anne Arundel, Baltimore, Baltimore City, Howard, Montgomery, and Prince George's) (Figure 1). The number of programs per county ranged from a minimum of 8 programs (Somerset, Cecil counties) to 24 programs (Baltimore City). About 15.5% of programs mentioned that their services are offered in all counties.

Table 4. The percentage of infant mortality programs in Maryland that mention offering services for a given demographic population based on review of websites and program documents

Demographic population	Number	%
Pregnant women	30	42.2
Infants/Children	14	19.7
Non-pregnant mothers/women	21	29.6
Fathers or family (mostly family, not specifically father)	8	11.6
Teens	17	23.9
Low-income, un- or underinsured	29	40.8
Racial/ethnic minority (incl. African-American, black women)	9	12.7
Rural communities*	36	50.7
Other**	10	14.1

Figure 1. Number of infant mortality programs by Maryland counties



What additional innovative approaches are used to support programs and their clients' needs? Finally, the website review also identified innovative strategies that some programs have adopted, which may better support the services offered or address their client needs. In particular, **outreach approaches** included hosting community baby showers to provide educational resources or infant care items, hosting information sessions or community input sessions in schools, communities, churches, and barbershop/hair salons, partnering with other local organizations, utilizing community health workers in at-risk communities, providing training online and frequently, and having a male involvement coordinator for teen programs. We also identified **supplemental or supporting practices** that could better support clients' or provider needs and goals. These practices included offering training that is online and provides continuing education credit, providing hospitals with specific designations (e.g., Baby Friendly Hospital), use of a reproductive life plan for preconception care, telehealth approaches (telephone/email consultations or hotlines), and peer support or group classes (e.g., group prenatal care, networking opportunities with peers). Most notably, many programs discussed other activities that provided additional non-health related services and resources. This included support of family needs (e.g., child care, transportation, GED support, meal planning), resources (e.g., cribs, doula, educational toys and books), or enabling services (e.g., language services, disability support). Several programs also discussed engaging in policy and advocacy related to their mission.

CONCLUSION

Summary of coverage

Overall, we identified 81 programs that focused on infant mortality or its risk factors in the state of Maryland, which were equally distributed between state, local, and non-profit or other types of organizations. While other programs in the state may address risk factors for infant mortality, this review focused on programs that provided preconception, prenatal, or postpartum care or services. The majority of services were concentrated around home visiting, health education, or referral/care coordination. These services can overcome barriers related to 1) awareness around health issues or concerns, such as pre-eclampsia symptoms or home safety, 2) transportation, by providing in-home visits, and 3) linkage and access to care, through coordinated referrals. Peer support/counseling and women's reproductive health services were also prominent. Additionally, and ideally, these services could be offered throughout the preconception, prenatal, *and* the postpartum/intrapartum period.

The programs mostly were targeted toward low-income populations within their jurisdiction with some mention of specific underserved minority populations. About half of all programs were in rural counties, but the highest number of programs were found in more populated counties. However, it was difficult to determine the reach or accessibility of these programs through web extraction methods, particularly in more rural areas.

Use of innovative approaches to reach clients

Another key component of the web extraction and review were approaches used to meet additional needs of the clients. In particular, innovative strategies included information sessions in a variety of locations, including churches and beauty salons, utilizing community health workers in high-risk communities, telehealth or hotlines for counseling or questions/concerns, and having a male involvement coordinator for the teen health programs. These strategies offer opportunities to bring services to the client and their community, particularly in settings that are familiar to potential clients. This has been shown to better engage and build trust within the communities and, in turn, maximizes reach to a larger number of clients and usability of services among clients.[3] Additionally, it was clear that some programs also service the broader needs of the clients by providing resources that address barriers to improving health or providing infant

[3] Black RE, Taylor CE, Arole S, Bang A, Bhutta ZA, Chowdhury AMR, Kirkwood BR, Kureshy N, Lanata CF, Phillips JF, Taylor M, Victora CG, Zhu Z, Perry HB. Comprehensive review of the evidence regarding the effectiveness of community-based primary health care in improving maternal, neonatal and child health: 8. summary and recommendations of the Expert Panel. J Glob Health. 2017 Jun;7(1):010908.

care, such as child care, GED preparation, or language services. In the case of outreach to providers, making training services accessible online and providing continuing education credit can also increase overall engagement in the program.

Identification of gaps

Gaps in services were also noted from this review. While many programs provided educational services, services that offer resources to enable clients to access care or address barriers to care were limited (e.g., language translation, cribs, adequate housing, child care). In particular, safe sleep resources were limited. While information may have been provided on safe sleep environments, only a few programs mentioned providing cribs to families, which has been shown to be an evidence-based intervention.[4] Mental health services and smoking or substance abuse were noticeably limited or not mentioned. This may be because these services are provided through referral and/or were not picked up given our inclusion criteria. Nevertheless, the time periods during and surrounding pregnancy (preconception and postpartum) are unique with specific needs that should be addressed within programs. Available mental health or substance abuse programs could further incorporate this special population in to their existing services. Additionally, resources to support breastfeeding, such as lactation consultants or breast pumps, or other nutrition services, apart from the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), were also less frequently mentioned.

Finally, specific programs focused on teen pregnancy prevention were limited (Table 2); however, we found that teens were mentioned more often as a special population within existing programs, such as family planning programs or programs for teen parents (Table 4). Of the teen programs mentioned by the state,[5] we could not identify which counties or communities were offering specific programs related to sexual education, rather the website indicated that funding is provided to local health departments or community partners who apply. Thus it was unclear, which areas offered comprehensive sexual education through Maryland's Personal Responsibility Education Program (PREP), sexual risk avoidance based on promotion of abstinence through the Sexual Risk Avoidance Education Program (SRAE), or both. Given that

[4] Moon RY, Hauck FR, Colson ER. Safe Infant Sleep Interventions: What is the Evidence for Successful Behavior Change? Curr Pediatr Rev. 2016;12(1):67-75.

[5] https://phpa.health.maryland.gov/mch/Pages/teenpreg.aspx

abstinence-only education has been shown to be less (not) effective,[6] there may be gaps in comprehensive services for teen pregnancy prevention if some counties only offer SRAE.

Overall, given the methodology applied, it may also be that some programs are addressing these services, but had not mentioned them on their website. There is also the potential to more explicitly incorporate these services in to existing programs within the state, such as during home visiting or through expanding pregnancy support and navigation services.

Study challenges and limitations

As mentioned previously, our findings are limited to mention of specific services on the website or within program documents. On the one hand, mention of services suggests that there is an explicit focus on this area within the program; however, it does not preclude programs from offering other types of services that may not have been cited in publically-available documents. Similarly, some information was essentially unavailable on websites, including program effectiveness, best practices, and challenges. The in-progress survey will address this data gap. Additionally, several students were involved in data collection and, thus, we cannot rule out variation in extraction details or quality. This is inherent in the design and methodology applied. Finally, it was difficult to determine the frequency in which the services mentioned are provided and the extent to which these services are distributed differentially within the state (i.e., are some services concentrated only in specific areas and mainly urban or more populated counties?).

The survey is currently being implemented to programs. Some initial challenges, which are being rectified, were limited or incorrect contact information on program directors or key personnel. Additionally, we are finding that multiple programs have the same program contact, which may increase participant burden. We also plan to provide a more targeted approach to emailing contacts with details on the specific programs in which to respond and citing that this study is needed to inform specific legislation for the state (2018 Md. Laws, Chap.83). We also hope to increase awareness of the survey through the MHCC workgroup networks.

[6] Santelli JS, Kantor LM, Grilo SA, Speizer IS, Lindberg LD, Heitel J, Schalet AT, Lyon ME, Mason-Jones AJ, McGovern T, Heck CJ, Rogers J, Ott MA. Abstinence-Only-Until-Marriage: An Updated Review of U.S. Policies and Programs and Their Impact. J Adolesc Health. 2017 Sep;61(3):273-280.