



# ASPE RESEARCH BRIEF

HHS OFFICE OF THE ASSISTANT SECRETARY FOR PLANNING AND EVALUATION  
OFFICE OF BEHAVIORAL HEALTH, DISABILITY, AND AGING POLICY

## STATE RESPONSES TO FASD: EFFECTIVE STRATEGIES AND ONGOING CHALLENGES

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### Introduction

Fetal Alcohol Spectrum Disorders (FASD) is a non-diagnostic umbrella term used to describe the range of disability that can result from prenatal alcohol exposure (PAE). FASD is estimated to affect as many as 11 to 50 per 1,000 children in the United States.<sup>1,2</sup> FASD affects individuals throughout their life course and the condition can involve cognitive, behavioral, and physical health issues.<sup>3,4,5</sup> The treatment and care of individuals with FASD can involve multiple systems on the federal, state and local levels, including the health care system (especially in the behavioral health care system), the child welfare system, the criminal justice system, and the long-term disability care system. The total lifetime costs have been estimated to be approximately \$2 million per affected individual.<sup>6</sup>

FASD is preventable, and much of the associated disability and costs to systems, families, and individuals can be reduced with the implementation of effective public health policies and programs. Since state agencies are positioned to have a significant impact on FASD policies, we provide an overview of successful strategies employed by various states. As comprehensive state FASD policies and programs must address three main components to adequately address the multiple facets of FASD--(1) prevention; (2) early identification; and (3) intervention--we organize this brief to provide strategies to address each of the three components.

This brief is based on findings from an environmental scan of peer-reviewed and grey literature and a meeting of nationally known experts on FASD that the Office of the Assistant Secretary for Planning and Evaluation (ASPE) held in September 2019 to discuss policies on prevention, identification, and interventions with individuals affected by FASD.

### Prevention of FASD

Employing effective prevention activities has great potential and can be more cost effective compared to identification and intervention strategies, particularly since there is currently no known cure for FASD.<sup>7,8</sup> Targeting prevention efforts toward all women,

including women of childbearing age who consume alcohol, is critical to reducing the incidence of FASD. Research indicates that nearly half of all pregnancies in the United States are unplanned, and the prevalence of alcohol use among non-pregnant women is 53% and binge drinking is 18%.<sup>9,10</sup> Due to the high prevalence of alcohol consumption and the potential implications of consuming alcohol at any time during pregnancy, broad-based prevention strategies could help decrease the incidence of FASD.

### ***State Strategies***

State strategies to prevent FASD include universal prevention such as education and outreach efforts to reach the population at large, selective prevention strategies targeted toward at-risk sub-populations, and indicated prevention strategies aimed at individuals who misuse alcohol.

***Universal Prevention.*** Proof Alliance, formerly known as the Minnesota Organization on Fetal Alcohol Syndrome, is a model of public/private partnership in universal FASD prevention.<sup>11</sup> This program includes prevention activities such as supporting community events in Minnesota to discuss the importance of planned, alcohol-free pregnancies, promoting alcohol-free beverages as an alternative to drinks containing alcohol, funding prevention grants for community stakeholders to engage in prevention activities, and promoting statewide public awareness campaigns.<sup>11</sup>

North Carolina has implemented a statewide universal prevention program, FASDinNC, which educates women of childbearing age and health professionals about FASD, its impact, and the importance of early identification and support.<sup>12</sup> The program also hosts a website that includes links to family and professional resources to help support healthy pregnancies, as well as including links to videos and podcasts regarding pregnancy planning.

***Selective Prevention.*** Alaska, which has established an office on FASD within its Department of Behavioral Health, has engaged in several selective prevention activities. The state supports the Native American Fetal Alcohol Spectrum Disorder Collaborative, an initiative of the National Organization on Fetal Alcohol Syndrome and the National Indian Health Board. The goal of these programs is to prevent FASD among American Indians and Alaska Natives (AI/ANs). In addition to selective prevention, these programs serve to improve outcomes for AI/AN children and adults living with FASD.<sup>13</sup>

The Minnesota-based Proof Alliance program supports selected intervention through the College Ambassadors Program, which provides funds to colleges and universities to host student events focused on preventing FASD.

***Indicated Prevention.*** The Parent-Child Assistance Program is a home-visitation program in Washington State which pairs mothers at high risk of alcohol-exposed pregnancies (AEPs) with case managers to help them address substance use issues and prevent future AEPs.<sup>14</sup> This program also maintains a database to inform future state policy and program evaluations.

## ***Challenges and Opportunities in Prevention of FASD***

Despite implementation of prevention strategies by several states, there are ongoing challenges and opportunities associated with these efforts.

- **Consistent universal prevention messaging.** The Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders (a federal group chaired by the National Institute on Alcohol Abuse and Alcoholism) recommends that prevention strategies such as public service announcements and screening and brief interventions should be universally applied to all women instead of select sociodemographic groups. States have an opportunity to encourage providers to share consistent, evidence-based guidance to all women, prior to conception, during pregnancy, and in the intrapartum period. Additionally, experts recommend that messaging should be coordinated across all agencies within a state, including social services, child welfare, public health, community health and behavioral health providers. States can also encourage insurers and managed care companies to incentivize alcohol cessation programs for women and enhance mechanisms for getting women rapid access to care when they present for it.
- **Positive prevention messaging.** FASD experts have surmised that prevention messages emphasizing the potential negative impacts on the unborn child are perceived to be a source of shame for women who drink while pregnant. This may contribute to underreporting of alcohol use by pregnant women. States could reframe FASD prevention to project a positive message to focus on a healthy pregnancy, according to experts. This could serve to reduce stigma and potentially help women take steps to obtain treatment. An opportunity exists for state government agencies to partner with marketing or advertising firms to create effective positive messages for FASD prevention.
- **Addressing FASD as a part of polysubstance use prevention.** Recent increases in funding for states as a result of the opioid epidemic present an opportunity to increase FASD prevention efforts along with substance use disorder (SUD) prevention efforts. Opioid use is often paired with use of other substances, alcohol and tobacco being the most common among pregnant and postpartum women with opioid use disorder.<sup>15</sup> To the extent that state agencies seek to address polysubstance use (which is the norm, rather than the exception for women with opioid use), broader substance use prevention strategies can also benefit reproductive age women with alcohol use disorder.
- **Screening and referral to treatment.** The Centers for Disease Control and Prevention (CDC) advises health care professionals to screen for alcohol misuse for all women, especially women of childbearing age.<sup>16</sup> However, due to lack of training and treatment options, health care professionals can be hesitant to screen for, identify, and provide referrals for women needing addiction treatment services. States also have an opportunity to implement policies that support evidence-based approaches in primary care settings to reduce risky drinking and increase effective contraception, which could reduce the risk of AEPs and

FASD.<sup>16</sup> One such approach (based on evidence and scientific consensus) would be incentivizing health care providers to screen all women of childbearing age using valid and reliable screening tools and provide brief guidance on the importance of alcohol abstinence if sexually active and not using contraceptives.

## Identification of FASD

FASD can be associated with a broad spectrum of physical, mental, behavioral, and cognitive disabilities, making identification challenging but necessary. Identifying and diagnosing an individual with FASD requires an in-depth assessment that can involve a physical exam, obtaining a comprehensive health history, standardized testing, and genetic consultation.<sup>17</sup> The experts that ASPE consulted recommended a multidisciplinary approach by a clinical team comprised of a pediatrician and/or a clinical geneticist/dysmorphologist and a psychologist for conducting neuropsychological/developmental evaluation. Teams may include speech pathologists, physical therapists, and/or other specialists.<sup>17</sup> Other strategies that states are implementing are described below.

### ***State Strategies***

States have implemented a number of strategies to improve FASD identification efforts. These strategies include screening, evaluation, and training efforts. Due to the number of individuals affected by FASD in the criminal justice and juvenile justice systems, some states have supported targeted identification efforts within these systems as well.

### ***Screening***

***Hennepin County FASD Screening Program.*** A program in Hennepin County District Court of Minnesota has succeeded in screening for and identifying FASD among youth who have been found guilty by the court. From 2008 to 2012, a significant number of youths were screened and subsequently diagnosed with FASD through this program, resulting in a better understanding of FASD among professionals treating youth and improved outcomes in recidivism and school success for the identified youth.<sup>11</sup> The University of Minnesota also operates a program within the state's school system to conduct screenings for FASD. This resulted in an increased number of at-risk youth being directed into appropriate intervention.<sup>11</sup> In addition, Minnesota's Department of Health screens for FASD in all newborns and provides mandated trainings for foster parents on parenting strategies for children with FASD.<sup>11</sup>

***Fetal Alcohol Spectrum Disorder Project.*** The Juvenile Delinquency Court of the Seventeenth Judicial District of Colorado has implemented the Fetal Alcohol Spectrum Disorder Project which works to identify youth prenatally exposed to alcohol and to ensure they receive a diagnosis and appropriate interventions.<sup>18</sup>

## ***Diagnosis and Evaluation***

In 1993, the Washington State Department of Social and Health Services and the University of Washington developed the Washington State FASD DPN [Diagnostic and Prevention Network]--a network of interdisciplinary diagnostic clinics.<sup>19</sup> This network is an effective approach to diagnosing FASD using interdisciplinary teams and a 4-digit diagnostic code. The code uses objective measurement scales, and specific case-definitions for diagnosing the full spectrum of outcomes observed among individuals with PAE. The code has four digits to reflect the four key diagnostic features of FASD including: (1) growth deficiency; (2) fetal alcohol syndrome facial features; (3) central nervous system structural and functional abnormalities; and (4) PAE. The code has been used to diagnose thousands of individuals in the State of Washington over the past 20 years. Additionally, the state has developed key policies in establishing Developmental Disabilities Administration eligibility for individuals diagnosed with the FASD code.<sup>20</sup>

## ***Challenges and Opportunities in Identification of FASD***

While several states have implemented successful screening programs, additional challenges and opportunities for improvement of identification of FASD remain.

- **A single, unifying FASD diagnosis.** The current lack of a single, unifying FASD diagnosis is a challenge to identification of this condition. Experts at the ASPE-convened meeting believe the field would be better served by a single diagnosis that harmonizes different diagnostic schemes, similar to the diagnosis of autism in which multiple disorders were collapsed into a single diagnosis of Autism Spectrum Disorder. The National Institute on Alcohol Abuse and Alcoholism (NIAAA) has convened a workgroup to review FASD classifications with the goal of harmonizing the various research classification systems for FASD. This might pave the way for consolidation of an FASD diagnosis and configuration of the FASD diagnostic criteria to address diagnostic subgroups or clusters based on functional status.
- **Multidisciplinary diagnoses.** A lack of resources to diagnose is also a challenge in FASD identification. This includes the lack of multidisciplinary teams to conduct thorough assessments, as well as lack of trained staff such as pediatricians, psychiatrists, psychologists, social workers, child welfare workers, occupational therapists and educators to improve recognition, screen, or refer out for diagnosis, affected individuals.

While a multidisciplinary team is recommended, there are other opportunities for establishing an FASD diagnosis. Telemedicine can be used to increase the availability of screening and diagnostic assessments. Teleconsultation, a mechanism using information and communication technology to provide either synchronous or asynchronous consultation, can be employed in areas that lack trained diagnosticians, such as rural areas. Models such as Project ECHO (<https://hsc.unm.edu/echo/>), which links specialists at academic medical centers with generalists in rural communities, could be adapted to expand FASD

resources. Programs that provide teleconsultation to pediatricians and family care practitioners, such as the program supported by the Massachusetts Child Psychiatry Access Program, also provide an opportunity for cross-disciplinary collaboration among providers.

- **Screening tools and processes.** Despite the existence of FASD screening tools, there is no agreed-upon universal screening process. One existing screening tool is an FASD checklist, which is included in the American Academy of Pediatrics FASD toolkit along with a number of resources and clinical guidelines for pediatric medical home clinicians to identify, diagnose, and refer children regarding FASD and ND-PAE.<sup>17,21</sup> While these resources are targeted for pediatric medical home providers, it could be adopted by other providers for more widespread use.<sup>22</sup> Also, technology, such as artificial intelligence, shows promise in assisting with screening for FASDs, including using face heat maps and photos taken by a mobile phone to improve screening for craniofacial dysmorphologies. Individuals with positive screens would be referred for further evaluation.
- **Training resources for professionals.** Frontline professionals from pediatrics, obstetrics and gynecology, nursing, health counseling, social work, early intervention, education, law, allied health, and other disciplines would benefit from additional training on FASD. There are several existing training resources, such as those developed by the American Academy of Pediatrics, to be adapted and marketed across health care professional disciplines. CDC provides a number of online training resources for FASD prevention, diagnosis and treatment for nurses, social workers, medical assistants, and physicians.<sup>23</sup> The Indian Health Service provides archived seminars on FASD through its Telebehavioral Health Center of Excellence.<sup>24</sup> Additionally, there are FASD champions such as physicians who work with CDC-funded grantees who could be tapped to provide talks and grand rounds for a variety of health care professionals focusing on screening, referral, and diagnosis of FASD.

FASD training resources are also available for legal and judicial professionals. In collaboration with the Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders, the NIAAA and the Office of Juvenile Justice and Delinquency Prevention collaborated with the American Bar Association (ABA) Center on Children and the Law, the National Council of Juvenile and Family Court Judges, State Bar Associations, and other partners to raise awareness about FASD and provide training to legal and judicial professionals. Training resources include an FASD technical assistance bulletin and an FASD bench guide for judges and continuing legal education on FASD for judges and legal professionals.

- **Payer policies and multidisciplinary evaluations.** Current state-level Medicaid reimbursement policies may prevent stacking of appointments or multiple appointments with different professionals within the same organization on the same day. Even when there are no state-based restrictions, providers may wrongly believe they cannot bill for multiple visits scheduled for the same

day. A careful review of state Medicaid policies coupled with provider education may help alleviate this issue. Emerging alternative payment models provide another way to resolve some of the funding concerns. Adapting the concept of the medical home, which is an emerging approach to providing comprehensive and high-quality primary care, could allow support for the multidisciplinary team needed for an FASD evaluation. The medical home approach is designed to build partnerships with clinical specialists, as well as families, and community resources and this collaborative approach could help support the team approach that identification of FASD requires. Funding for care coordination as a part of alternative payment models could be used to pay for coordination of assessment appointments as well as the interpretation of the assessments. The Virginia Medicaid system supports a “preferred” clinic category that could be used to support FASD diagnoses. These clinics receive a higher per member per month payment that could be leveraged to cover FASD screening and diagnosis costs that are not currently covered.

## **Interventions for Individuals with FASD**

Once individuals are accurately diagnosed, interventions can be implemented to lessen the impact of FASD, with early interventions generally having the greatest potential impact on developmental outcomes.<sup>25,26</sup> Intervention approaches vary by specific FASD disorders and individuals. Some experts recommend that interventions for FASD begin with a comprehensive psychological examination to evaluate deficits and create a tailored care plan. In order to successfully implement behavioral interventions, providers must understand the needs of children with FASD at each stage of development.

FASD is a multifaceted condition, and many different types of interventions can be utilized.<sup>27,28</sup> There are evidence-based interventions to address different functional deficiencies related to FASD. For example, the Good Buddies program addresses social skills; the Families Moving Forward program targets challenging FASD behaviors; the Math Interactive Learning Experience (MILE) program helps address mathematics difficulty; and Parents and Children Together (PACT) can improve self-regulation of individuals with FASD.<sup>29</sup>

### ***State Strategies***

States have implemented a number of strategies to serve individuals with FASD and their families, once an individual is diagnosed. Several states provide educational supports and supports for individuals within the criminal justice system.

### ***Educational Supports***

Alaska has integrated support for FASD into its education system, allowing individuals with FASD to have access to special education services.<sup>30</sup> Through an education regulation change, FASD is included in the list of conditions under the special education category “Other Health Impaired”. The policy, enacted by the Alaska Department of Education, also expands who can diagnose a health condition to include advanced

practice registered nurses in addition to physicians. Children with FASD can be automatically referred for special education services and can receive an Individualized Education Plan (IEP) or services under Section 504 of the Rehabilitation Act of 1973, depending upon level of assessed need.

### ***Criminal Justice System Supports***

Research suggests that individuals with FASD are over-represented in the criminal justice system, underlining the importance of state strategies to identify and support these individuals.<sup>31</sup> Alaska has implemented several policies to support training on FASD for parole officers, judges, district attorneys, and public defenders. Sentencing in the state also must consider FASD as a mitigating factor and allows greater flexibility in sentencing people with FASD in these cases. A state law passed in 2012 allows judges flexibility in sentencing people with FASD in certain cases where there is clear and convincing evidence that the defendant's judgement or behavior was impaired due to a FASD diagnosis.<sup>32,33</sup>

State bar associations, in conjunction with the ABA, also represent an important resource in supporting individuals with FASD. In 2012, the ABA passed a resolution to encourage improvement in legal representation for individuals with FASD; increased access to FASD screening and assessment; attention to the disproportionate number of individuals with FASD in the child welfare and criminal justice systems; and the use of knowledge of an FASD diagnosis in the mitigation of sentencing and to access comprehensive treatment services.<sup>34</sup>

### ***Challenges and Opportunities in Intervention***

While states have supported a variety of strategies to address interventions for individuals diagnosed with FASD, there remain additional challenges and opportunities.

- **FASD in disability definitions.** State and federal disability definitions do not currently include a mechanism for FASD to be included among qualifying disabilities, and most individuals who qualify for disability services do so through co-occurring diagnoses. The FASD diagnostic category is also absent from many state and local program disability definitions that could support needed services and interventions. This includes the educational system, corrections, child welfare, behavioral health, and other agencies. Opportunities exist for the addition of FASD to disability definitions, for example, FASD can be explicitly added as qualifying conditions for eligibility for Individuals with Disabilities Education Act Part B. This could enable children with FASD to be eligible for IEPs.
- **Model FASD programs.** Opportunities exist for model programs to expand outreach efforts through implementing tele-psychiatric consultation for pediatric providers and provision of training to support implementation of effective programs such as MILE, PACT, and the Language to Literacy Program.



- **Reimbursement for services.** Since FASD is not included in many disability definitions, reimbursement for services is typically tied to a co-occurring disorder; therefore, service needs are addressed in an uneven fashion. Alternative payment models may offer solutions in paying for identification and provision of services and supports for children with FASD. For example, the Integrated Care for Kids Model (<https://innovation.cms.gov/innovation-models/integrated-care-for-kids-model>), a child-centered local service delivery and state payment model designed to reduce expenditures and improve the quality of care for children covered by Medicaid, could be used by states to increase screening and treatment of children with FASD.

## **Comprehensive State Strategies**

Many states have also engaged in comprehensive strategies to support FASD prevention, identification, and intervention activities. The most frequently employed strategies include state workgroups and task forces and state policies.

### ***Workgroups and Task Forces***

Many states address the complex problem of FASD through the use of workgroups or task forces. Besides focusing their efforts on prevention activities, they also provide support for intervention activities.

In 1997, Minnesota convened a large, multidisciplinary Governor’s Task Force to develop a comprehensive state approach to prevent and reduce harm from FASD. The group’s report provided the impetus for approximately \$5 million in funding for universal prevention efforts such as public awareness campaigns, special treatment programming, and research on the incidence of FASD in the state. The funding also supported the creation of a state FASD Coordinating Board and supported indicated prevention including policies for voluntary reporting of alcohol use during pregnancy.

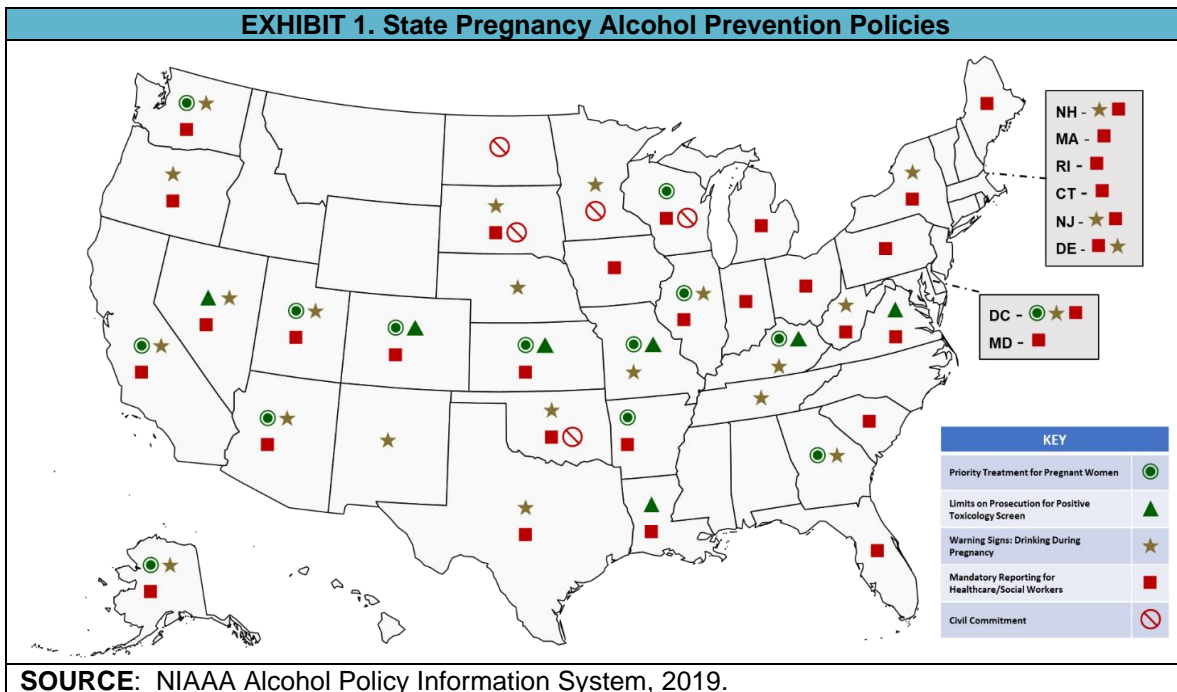
New York State has established an FASD workgroup to increase awareness, prevention and treatment through enhanced collaboration and coordination.<sup>35</sup> The group has four focuses: (1) increasing public and professional awareness of FASD; (2) decreasing the number of women who drink alcohol during pregnancy; (3) improving the quality and accessibility of diagnostic and referral services for individuals with FASD; and (4) improving the quality, accessibility, and continuity of treatment for individuals with FASD.

### ***State Pregnancy and Alcohol Policies***

In the alcohol use prevention and treatment literature, policies targeting alcohol use among pregnant women have often been categorized as “punitive” or “supportive”; the first group including policies such as civil commitment laws and mandatory reporting for child abuse and neglect, and the latter including policies such as priority treatment for pregnant women or prohibition against criminal prosecution for drinking during pregnancy.

In recent years, states have focused on reducing or preventing women’s alcohol use during pregnancy through the implementation of statewide policies specifically targeting alcohol use and other substance use during pregnancy. The enactment of such policies has grown nationally moving from one state with an alcohol and pregnancy policy in 1974, to 43 states in 2013.<sup>36</sup> These policies, however, have been increasingly punitive, subjecting pregnant women who use alcohol and other substances to extra scrutiny and greater ramifications, including court-ordered separations of mothers from their children.<sup>37</sup> A review of state policies has suggested that supportive policies, such as priority treatment of pregnant women with SUD, could have potential to effectively support pregnant women and women with children by providing access to treatment; however, there have been no outcome studies to date.<sup>38</sup> Some studies have found that punitive policies are not associated with improved birth outcomes and that they are associated with women avoiding prenatal care.<sup>2,38,39</sup> However, both “supportive” and “punitive” policies have been associated with outcomes that affect negatively infant development<sup>37,40</sup> and none of the policies have been effective in reducing alcohol consumption among pregnant women.<sup>41</sup> More research is needed to understand how policies can be built utilizing public health approaches and expert opinions in order to be effective in reducing PAE.<sup>42</sup>

**Exhibit 1** provides a listing of the types of policies that states have adopted to reduce or eliminate substance use, including alcohol, for women who are pregnant and of childbearing age. Many states have a mix of punitive policies such as civil commitment and mandatory reporting by health care workers and social workers of pregnant women who are actively using alcohol, neutral policies such as warning signs about drinking during pregnancy posted in retail stores and limits on prosecution for positive toxicology screens, and supportive policies such as priority SUD treatment for pregnant women.



## Conclusion

States have engaged in multiple strategies to aid in the prevention and identification, and intervention within individuals adversely affected by PAE. By supporting state task forces and coordinating workgroups, prevention campaigns and policies, innovative identification processes, and effective treatment interventions, many states are serving individuals with FASD and their families. FASD-focused prevention, identification and intervention activities would continue to benefit from enhanced and expanded attention from state policy makers working closely with health care and social services communities.

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