2017 WEST VIRGINIANS FOR AFFORDABLE HEALTH CARE

Kids' Health

ROUNDTABLE SERIES

Prenatal Substance Abuse and Exposure: Challenges and Recommendations

About the Roundtable Series

Twenty years ago, the Children's Health Insurance Program (CHIP) was enacted. It was created with bipartisan support by Congress and championed by West Virginia Senator, Jay Rockefeller.

It was enacted with bipartisan support in West Virginia in April, 1998.

The significance in the creation of CHIP has evolved over the years, but the fundamental reason for its creation remains simple— a population of children was not adequately insured. Because of this, stakeholders and advocates rallied in support of better health care for these kids. For a time, their health became a national priority. Legislators from both sides of the aisle, policy makers, health advocates, and community activists joined in support of a program that not only addressed the insurance needs of a population they felt were "falling into a gap" in coverage, but meaningfully and thoughtfully discussed the health care needs of a population that, like children covered by Medicaid, often had special needs that were going unmet.

Now, 20 years later, West Virginia's kids face a myriad of new challenges-- very different than the ones from previous generations. Poverty, health disparities, the opioid epidemic, sedentary lifestyles and physical inactivity, the massive growth in the fast food industry, "screen time" issues, virtual bullying-- these have significantly changed the health care needs of children and adolescents in our nation and state.

And so, questions we pose to this generation's children's health providers, stakeholders and advocates are: Are we up to the challenges that our predecessors were 20 years ago? Can we be the visionaries of today and address the issues that threaten the health of West Virginia's kids? Will we make children's health care, for this moment in time, a priority?

To answer these questions, West Virginians for Affordable Health Care (WVAHC) held the 2017 Kids' Health Roundtable Series. We are grateful to the hosts, moderators and panelists who volunteered their time and expertise to answer these important questions, address these challenging issues, and recommend next steps to improve the lives of West Virginia's kids.

With everyone's help, we believe our state is again ready to make children's health a priority.

The following report is a summary of the discussion held at the September 15, 2017 Roundtable in Huntington, hosted by Marshall University Joan C. Edwards School of Medicine.

Kids' Health ROUNDTABLE SERIES

Key Issues for Substance Exposed Newborns: In Search of Solutions

When selecting topics for each roundtable in the series, WVAHC struggled to find four issues that addressed key challenges that kids currently face in our state, as well as generate meaningful recommendations to address them. Sometimes we can become so overwhelmed by the sheer breadth of the adversity, we forget to balance the dialogue with potential solutions. This has resulted in many missed opportunities for significant change.

The topic, *Prenatal Substance Abuse and Exposure and Neonatal Abstinence Syndrome (NAS)*, was one we felt required to address.

Currently, one baby born every 25 minutes in the United States is born suffering from opioid withdrawal, according to the United States Government Accountability Office.

In West Virginia, 2016 state health statistics show that for overall births in our state, 1 in 7 babies were born exposed to substances, and among those, 1 in 3 have NAS. This is the highest prevalence rate in the country.

Because of this, WVAHC knew the challenge of addressing the unmet health care needs of drug-exposed newborns was one that must be undertaken — by advocates, by providers, by policymakers, by legislators, and by communities.

The roundtable was held in Huntington, often referred to as "ground zero" for the opioid epidemic. According to the Center for Disease Control and Prevention, Huntington has the highest rate of opioid overdose fatalities in the nation-- nearly 10 times the national average.

Challenges and Recommendations

West Virginia currently leads the nation in children born exposed to drugs, as well as in opioid overdose fatalities. The epidemic has devastated Appalachia, but drug addiction is not new to the region. The deep, systemic, and pervasive roots of poverty have always had a deep hold on our state, resulting in increased drug dependency. The strength and effects of the drugs now prevalent in our communities have created mass devastation, unlike we've ever known, that will negatively affect generations of children — primarily, those born exposed.

Because of this, WVAHC partnered with the West Virginia Perinatal Partnership to bring experts from around the state to discuss these challenges, as well as recommend solutions.

Challenge: The nature of illicit drug use in West Virginia has evolved in reaction to systemic social, economic and community forces that have plagued our state for generations.

In the 1990s, in an effort to better treat pain, doctors overprescribed opioids, unaware of the global consequences. Experts at the time contended that pain had been undertreated in routine medical practice. Pharmaceutical companies took advantage of this, and painkillers proliferated the region. What has resulted is a dramatic increase in drug use, overdoses, overdose deaths, and infants born exposed to opioids.

As a state, how did we get here? How did West Virginia become the state hit hardest by the opioid addiction crisis that has swept the country over the past 10 years? What are the next, most logical steps to "turning off the faucet" of demand? And how do we use the answers to these questions to inform policy change?

The panel recommended:

1. *Address West Virginia's cultural dependency on pharmaceuticals:* Historically, our state has had a cultural reliance on pharmaceutical solutions to health problems. Currently, our state Medicaid program

> *A tsunami of need is coming. We need to fund it on the front end – try and get a handle on this before it gets further out of our control.*
>
> *Senator Ron Stollings*

reports that 50,000 prescriptions are filled each day, and that the average Medicaid member fills 25 prescriptions per year. The national average is 12. This, the panel agreed, says something about how we deliver health care in our state, as well as the physical demands of a workforce that cannot miss work days due to injuries. We must find more solutions than just with medication. At the root, our heavy reliance on pharmaceutical solutions translates into our over-reliance on pain medications.

Recommended national policy changes should be adopted on the state level. We should more actively use prescription drug monitoring programs to identify suspicious patterns of opioid use. Insurers need to cover effective non-opioid pain remedies and understand that if ineffective, patients may be struggling with deep-seated social and economic ailments that may never completely yield to medical remedies. Medication such as naloxone and drug rehab cannot cure joblessness, poverty, lack of economic opportunity, and the hopelessness that results. That will require economic, not addiction, rehabilitation.

2. *Address the stigma:* The stigma of addiction faced by pregnant women who use opioids directly affects whether they seek prenatal care to mitigate the severity of NAS. Among other things, the stigma may prevent pregnant women from seeking treatment or prenatal care, prevent them from disclosing their drug use to health care providers, or cause the women to fear punitive effects, lose custody of their children, or lose their jobs.

The panel suggested a public service campaign to address the importance of overcoming stigma to seek health care. The campaign would be West Virginia-specific and created in conjunction with the West Virginia Department of Health and Human Resources and community groups. Public Service Announcements could run in a variety of non-traditional settings to reach this key demographic, which rarely utilizes health care.

3. *Start prevention efforts earlier, and more comprehensively:*

- In schools: West Virginia should start drug education and prevention efforts in elementary schools, and continue them through every year. With the advent of passed legislation in 2017, requiring drug awareness and prevention programs for all K-12 students, our state is in a unique position to address the opioid crisis and drug use in a way it never has before.

However, it must be done in a more realistic, comprehensive way than in previous years. “Just say no” and other messages that promote avoidance of drugs as a singular message are unrealistic and unhelpful. Many students are already living in circumstances where drugs are a part of their lives, so addressing stigma in the school setting is key. Stigma can prevent parents and teachers from speaking with children about the dangers of opioids, prevent individuals struggling with opioid addiction from seeking the treatments they need and prevent cities and counties from providing these treatments. Because of this, drug curriculum should be factual, sensitive to the real use and lifestyle, and done with care coordination and referral of services, so we can educate, normalize the stigma and develop connections and linkages with resources and services, so children can be referred into social supports as needed.

Also, schools should comprehensively encourage healthy behaviors that go well beyond resistance to substances. This includes utilizing Positive behavior support (PBS)-- a behavior management system used to understand what maintains a student’s challenging behavior.

Further encouraging healthy behaviors within the community could be achieved by allowing school systems to become extended community support systems, where services could be “housed” and coordinated. Especially in rural areas, the community school concept could provide more support mechanisms that would directly support families and provide a sense of connectedness.

- *In-home visitation programs:* First, in-home visitation programs can provide a critical opportunity to address issues of stigmatization of drug use. A health professional can help a mother discuss her fears of stigma in a private and safe setting.

  Second, through in-home visitation programs, case managers can address the health and social well-being of mothers in adverse circumstances by linking clients with appropriate service providers to help in obtaining treatment, maintaining recovery, resolving the complex problems associated with their substance abuse, and to guarantee that the children are in a safe environment, receiving appropriate health care.

  As noted by the panel, there are currently no waiting lists for home visitation programs. As they are utilized on a volunteer basis, all health care and community service providers can promote and advocate for the use of these programs. A comprehensive referral approach should be developed.

4. *Meaningfully address our fragmented treatment system:* The panel called for needs assessments, specific to each community, so they are addressing the drug crisis strategically at the local level. For example, primary care providers can play a very active role in addressing the service needs of those with substance use disorder (SUD), particularly in more rural areas where there are no specialty services.

For years, there have been efforts in our state to recruit and retain behavioral health workers, but these efforts rarely include providers who work specifically with pregnant women with SUD, as well as the special behavioral health care needs of children who are born exposed, and/or suffer trauma in environments.

The panel agreed that greater availability of Medicaid coverage has increased services to satisfy the growing need for treatment. However, pregnant women are far more likely to encounter waitlists, and many are unaware of the potential treatment options they have. Again, a call for a public awareness campaign was suggested as a way to let women with SUD know that options are available to them, if they're interested in treatment and recovery.

Community assessments also help address trauma at the local level. The drug epidemic has many first responders and health care providers dealing with not only others' trauma, but their own trauma as well. Such community planning helps create reform that is thoughtful, rather than reactionary, and addresses the "waves" of needed services.

Challenge: Our state is in unchartered territory in dealing with the opioid crisis, and this is especially true when it comes to treating the women and children affected by this epidemic. There are few studies that have researched the long-term health effects of NAS. Current information suggests developmental disabilities, learning disabilities, and behavioral problems. Then when factoring in environmental stressors — many of these children are living in the same or similar environments as they did in utero — children have pronounced, often long-term mental health care needs that will need to be addressed in a variety of settings, such as in school.

Unfortunately, the government systems that provide services for children are fractured and rigid. While teachers, community service workers, health care providers and clergy have expressed antidotal concerns that children born exposed have exhibited developmental delays and impulsivity control issues, these systems have little to no data on which to base strategic next steps and are ill-prepared to deal with their health care needs. While we know that longitudinal studies are needed, we must adapt the way we care for these women and children now, as they have very pressing needs.

And so, beyond the devastating death toll and the economic costs, the drug epidemic is also costing the families that are ripped apart and generations of lost potential and opportunity.

What can we collectively do, across systems, to get our arms around the massive problem in such a way that the State and subsequent systems can strategically address the needs of women with SUD and their unborn children?

The panel recommended:

1. *Embark on a longitudinal study:* There is a lack of studies investigating the longitudinal outcome for children born of mothers with opioid and poly-substance abuse disorder during pregnancy. Such a study could not only revel the medical needs, but also the needs in care coordination between systems. The panel strongly advocated that the State begin working on this effort.

2. *Focus on home visitation programs:* Again, panelists recommended more marketing and referrals to home visitation programs. Substance abuse interferes with mothers' parenting skills by decreasing awareness and sensitivity to their children, and impairing judgment abilities. Providing support and intervention is crucial to reducing the negative developmental impacts of substance abuse on young children. A more integrated, culturally-sensitive approach to the treatment of pregnant women and young mothers with substance abuse issues and their infants will decrease negative outcomes.

3. *Collect, improve and connect comprehensive medical records:* The only way to learn more about the long-term health care needs of babies born exposed is to capture relevant data in their medical records. These records should not only follow them through the course of their lives and experiences with the health care system, but also in such relevant systems as public education, foster care and juvenile justice. Currently—from pregnancy to child-rearing—we're not capturing data and sharing it between providers and systems. Physicians aren't sharing with OBGYNs. OBGYNs are not sharing with pediatricians. Children in foster care rarely have comprehensive records; foster parents rarely know what these children have been exposed to, their health history, prescriptions, etc. Schools have little to no knowledge of previous drug exposure of their students.

Furthermore, often documentation is not complete or recorded properly. Improper coding, for example, can skew data collection. The importance of appropriately collecting significant data on all patients is vital to any longitudinal study. Some providers must overcome the mindset that documenting drug exposure in a patient's chart is "labeling." If drug use isn't recorded, how can we keep from misdiagnosing NAS children as they grow older?

The panel strongly advocated for better documentation in health records—from appropriate coding, to sharing data with other health care providers, as well as systems such as foster care and public education, when appropriate.

4. *Coordinate care between practices and systems:* Currently, over 6,200 children are in foster care in West Virginia. Around 80 percent is due to drug abuse. And still, cuts have continued at WVDHHR for a handful of years, while this number of displaced children has risen exponentially. The panel called for innovation—to connect more recovery programs with home visitation program, visitation programs with behavioral health services, and health care with public school systems. While this would be a large, new undertaking, integrating systems is crucial to connect the safety net, so children don't fall through the cracks.

This care coordination includes integration within health care practices, with the goal of shepherding women who can become pregnant toward birth control and recovery services, motivating pregnant women toward accessing health care and recovery services, and shepherding new moms toward home visitation, community programs and as always—recovery services. A multi-disciplinary approach to staff training to identify and care for pregnant women with SUD is key. Also is connecting with community services once the baby and mother are discharged, to ensure the child is going home to a safe environment.

The panel agreed that every system that cares for kids who were born exposed must have a plan to address their health care needs. Their increasing prevalence warrants it.

Challenge: Our state traditionally lacks providers, resources, and particularly funding to address public health challenges, and the opioid epidemic is no different. However, pockets of communities, organizations and individuals around our state have successfully begun addressing the challenges and unmet health care needs of these mothers and newborns. What are we doing well? What should we expand on and replicate?

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The panel recommended:

1. *Standardize universal screening:* The dramatic increase in illicit and prescription drug use should prompt a statewide universal drug screening program for moms delivering in hospitals across the state. It should be a dual screening program for both moms and newborns. Since early diagnosis and treatment achieves the best outcomes, early detection is critical. The program should be consensual; if mothers do not consent, their babies should be tested instead. When possible, women identified with SUD should be referred to the appropriate services. Screening for substance use should be a part of comprehensive obstetric care and should be done at the first prenatal visit in partnership with the pregnant woman. Multidisciplinary long-term follow-up should include medical, developmental, and social support. Infants born to women who used opioids during pregnancy should be monitored for neonatal abstinence syndrome by a pediatric care provider.

Cabell-Huntington Hospital and J.W. Ruby Memorial Hospital are examples of two of a small but growing number of hospitals nationwide that conduct universal screening to treat infant substance withdrawal.

2. *Expand "rooming-in with mother and newborn" programs in hospitals:* Infants born to women who are dependent on opioids are likely to experience withdrawal symptoms during the hours and days following birth. Several studies have demonstrated that babies allowed to room-in with their mothers experience less-severe signs of NAS and are less likely to require pharmacotherapy and prolonged hospitalization. Rooming-in allows for more successful bonding and results in a greater likelihood that babies will remain in their mothers' custody at the time of discharge. Although hospital space for such a program is hard to come by, the panel encouraged for "research to drive the discussion" and for payors, hospitals and programs to fund rooming-in programs.

3. *Integrate approaches:*

- Between OB/GYNs and pediatricians – An interdisciplinary task force of obstetric, pediatric, nursing, and administrative support should work collectively to discuss issues related to high-risk mothers and newborns, plans of care, expected delivery dates, and to make all information via consultations available to the task force.

- Between health care and community resources – A successful example of this in our state is the Drug Free Mother Baby Program. Through the program, mothers are linked to integrated maternity and behavioral health services, as well as linked to community resources such as the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) and Right for the Start, recovery coaches, therapy services, etc. The panel agreed that a staffer trained in the program should be in every OB/GYN clinic in West Virginia.

- Between health care, recovery coaches and Child Protective Services- So a collective approach can be made to identifying environments as safe for children.

- With harm reduction clinics – Harm reduction clinics are a public health strategy with well-documented results in reducing morbidity and mortality. Many of West Virginia's clinics have successfully integrated sexual health education in an attempt to reduce teen pregnancies, sexually transmitted diseases and the number of children born exposed to drugs.

  The panel noted that these clinics serve as an entry point for services for women with SUD; it was widely agreed that these women wouldn't walk into a clinic without the needle exchange program. And so, these clinics are a way to bring women into care, and hopefully recovery.

Challenge: To respond to the drug epidemic, we must make responsive changes in the way we care for those with SUD and the children who are born exposed.

But systems are often rigid, and updates to policies and practices are needed to meaningfully and comprehensively address these issues. What sound policies can the West Virginia Legislature pass to better enable treatment and prevention? To empower providers? And to promote coordination and a systemic response to make formidable change?

The panel recommended:

Changes within the health care system: While the panel agreed that there should be a further reduction of prescribing opiates, the problem itself is not the drugs. In fact, prescription drugs are in many ways "safer" than heroin and street drugs. Trauma, poverty, a lack of "hope" are root causes for drug addiction. Without trauma-informed care and behavioral health services, we will never alleviate the drug problem in our state.

And, the full continuum of addiction services, including medicated assisted treatment, as well as behavioral health treatment, must be available to all who are ready — including pregnant women. A strategic plan to recruit and retain providers who will treat pregnant women is crucial to this continuum of care.

Primary care should also take a more substantial role in addressing the needs of patients with SUD by regularly screening patients, providing early care and by providing care coordination when needed. Trauma screening and screening for alcohol and substance use by utilizing approaches like Screening, Brief Intervention, and Referral to Treatment (SBIRT) need to be integrated into all primary care settings, including pediatrics and OB/GYN.

Changes within the legal system: Many in recovery are connected to care through drug courts. The panel agreed that these courts are effective and should be implemented in every county in the state.

There are significant challenges to standards in how we penalize drug use. Standards are not standards when variations in the legal system change from county to county. A statewide level of standards should be determined, rather than a local determination, so treatment for SUD patients wouldn't have to change due to where the patient lived within the state.

Changes within the child welfare system: Child Protective Services (CPS) workers should develop relationships with health care providers, to bridge gaps in differences of opinion as to what is considered a "safe environment" for children. Sometimes, what the CPS worker is seeing is not the same as the health care provider. A professional relationship between health care and CPS should be established.

The panel overwhelmingly agreed that when it's safe to do so, children should stay in the care of their mothers and families. If it takes a "village mentality" to do so, then communities should develop policies and protocols to work together to assist and educate families.

Changes within public education: The panel agreed that public education was a key, crucial setting in which to share prevention services, as well meet health care needs—particularly trauma-informed care.

Since a recent law was passed this year that required opioid awareness and prevention programs into the curriculum in all grade levels, it's a prime opportunity to address stigma and teach drug prevention in a sincere, informed manner.

The panel agreed that the most important thing we can do is to "turn off the faucet and help those still caught in the pipeline." Schools were considered a key setting in which to do this.

Changes with legislation: The panel expressed concern over potential legislation that would remove newborns from the custody of mothers and incarcerate them if they tested positive for drugs during pregnancy. The panel agreed that penalizing mothers via incarceration or terminating parental right was not in the best interest of the child or mother. The panel urged legislators not to "legislate due to feelings." An educational campaign specific to legislators was suggested, so proposed bills would be based on evidence and valid information.

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About the West Virginia Perinatal Partnership and West Virginians for Affordable Health Care

The West Virginia Perinatal Partnership is a statewide partnership of healthcare professionals and public and private organizations working to improve perinatal health in West Virginia. Founded in 2006, the Partnership coordinates programs and develops policies to address the State's health outcomes among mothers and their babies.

Since the Partnership was created, many achievements have been made to improve the perinatal system in West Virginia and these were documented in "Accomplishments of the West Virginia Perinatal Partnership from 2006-2012." The members of the Central Advisory Council, Steering Committee and health care professionals throughout the state who serve on the Partnership's committees, continue to work on addressing the many problems that impact the health of our mothers and babies.

To learn more, visit **http://www.wvperinatal.org/**.

West Virginia Chapter of the American Academy of Pediatrics

WVAHC West Virginians for Affordable Health Care Consumer Voices for Health Care

The mission of West Virginians for Affordable Health Care is to bring a consumer voice to public policy so that every West Virginian has quality, affordable health care and the opportunity to lead an informed, healthy and productive life.

We achieve our mission by:

- Working with partners to identify and advocate for positive public policy change.
- Developing and coordinating innovative public education programs.
- Protecting and preserving programs that serve our mission.
- Assisting individual consumers in navigating the health care system.

To learn more, visit **www.wvahc.org** or email **info@wvahc.**

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