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FOLLOW UP

Infants and the Opioid Epidemic: Leveraging Coordination, Data, and Leadership

C4CJ prepared highlights from Dr. Loren Robinson's presentation

- The Pennsylvania Department of Health (DOH) and Department of Human Services (DHS) are meeting to explore what the world of Neonatal Abstinence Syndrome (NAS) in PA looks like.
- On the NAS data front, state leaders recognize that the state has some information about infants on Medicaid. Then DOH has some information based on hospital discharge data. Overall there is not one robust data set. There are a lot of holes here.
- PA is not ready at this moment to report data on NAS, but DOH Secretary and the Governor are taking it very seriously and working to find the best path forward on the data.
- Wolf Administration feels strongly that there be a universal lens on this so not penalizing or criminalizing moms or any demographic. We need focus on both legal and illegal drugs and take a very holistic approach.
- Brining on maternal and child just focus on maternal and child health issues – need some good public health surveillance. Important, however, that work not just be about counting kids but getting connected to services, getting a plan of safe care.
- Discussions with DHS have initially focused on what entity initiates the plan of safe care and having that plan initiated with DHS after families leaves the hospital. However, that invites some concerns about the gap between hospital and home. So now leaning toward having the plans of safe care initiated from the hospital. That will necessitate bringing hospitals to the table from the beginning. It is a very fluid conversation, the more input the better.
- DOH is working on a decision memo to send to DOH Secretary Murphy among the items in that memo is to propose that NAS be added to the newborn screening process to screen every newborn for NAS. Seeking feedback from stakeholders about best approach. In order for something to be included in newborn screening there must be some type of test utilized. Initially, DOH was thinking that the screening be done through meconium screens on every baby and are working to roll that into the DOH budget (2016-2017) budget request. Initial estimates are that approximately $500,000 would be needed for the first year and looking to see if can be pulled from maternal and child health block grant in case there is not an appropriation of state funding.
- Also working, via their Chapter 27 regulations (Communicable and Noncommunicable Disease), to add NAS as a reportable health condition as the first step and then moving to add the newborn screening dimension to reach all children.

  C4CJ note: Here is a link to the current list of "diseases, infections, and conditions" to be reported to the PA DOH -

http://www.health.pa.gov/My%20Health/School%20Health/Documents/Communicable%20Diseases/DISEASES%20TO%20BE%20REPORTED%20TO%20DEPARTMENT%20OF%20HEALTH.pdf

Q&A with Dr. Loren Robinson (LR) and Dr. Michael Warren (MW)

At the end of the September 15th event, there was some time for general discussion and to put forth some questions. Below is the notes/summary of that discussion and Q&A.

Question: Using meconium sample separate from the existing blood prick and what will you be screening for? Noted as well that many babies impacted by opioids are affected by other substances, including nicotine.

LR: DOH hasn't picked a screen and she acknowledged that many are commercially available. For now the consideration is to proceed with screening via a baby's meconium, but DOH is quite open to feedback.

Question: The speaker noted being "impressed" with TN's presentation, especially in the context of a state that enacted a criminal statute aimed at pregnant women and defunded Planned Parenthood. Also it was noted that the current dialogue and agendas bear a close resemblance and merit caution based on what we already know from the crack epidemic. There was a note of concern that today's discussion did not address the degree to which women who suffer from substance use disorders are women who, as children or adults, have experienced trauma (e.g., child abuse, sexual assault, domestic violence). That lens requires then further discussion about the need for/availability of gender-specific, trauma-informed, and culturally-informed substance abuse treatment. A specific question was then raised about what the purpose is behind any widespread screening given existing limitations on access to treatment services? TN was applauded for collecting data and building a public health surveillance infrastructure, but more insight about treatment efforts was needed. It was underscored that this discussion – today and each day forward – must be intentional in avoiding negative, punitive approaches to pregnant women and infants.

C4CJ notes:

- **Senate Resolution 267** - In August, the Joint State Government Commission (JSGC) began work required of the agency by Senate Resolution 267 (sponsored by Berks County Senator Judy Schwank). SR 267 required the JSGC "to study issues relating to the need for, availability of and access to effective drug addiction treatment" in Pennsylvania.[1] HR 267 required that JSGC convene an advisory committee and JSGC was directed that among the included members must be a representative from both the PA Coalition Against Domestic Violence (PCADV) and the PA Coalition Against Rape (PCAR). Here is the link to the JSGC study - http://jsg.legis.state.pa.us/ongoing-projects.cfm?JSOP_ONG_PROJ_ID=57.
- **House Resolution 590**(sponsored by Philadelphia Representative Stephen Kinsey) was adopted by the PA House of Representatives in May.[2] As a result, PA's Department of Drug and Alcohol Programs (DDAP) has established and will administer "a task force on access to addiction treatment through health plans and other resources." DDAP convened the first meeting of this task force on September 6th and five additional hearings will be convened.[3] Members of the Task Force can be found at this link - http://www.media.pa.gov/pages/DDAP_details.aspx?newsid=39. Public comments about access to treatment can also be offered at www.ddap.pa.gov.

MW: Thank you, hit at crux of the issue – we have the data so what are we going to do with it. We tried to implement brief screening at a population level and then refer certain individuals, based on that

[1] http://www.legis.state.pa.us/cfdocs/billinfo/billinfo.cfm?syear=2015&sind=0&body=S&type=R&bn=267
[2] http://www.legis.state.pa.us/cfdocs/billInfo/billInfo.cfm?sYear=2015&sInd=0&body=H&type=R&bn=0590
[3] http://www.media.pa.gov/pages/DDAP_details.aspx?newsid=40

screening, to treatment. We have had challenges. We can screen all day long and found in TN's pilot that there were not necessarily community mental health treatment services let alone those that are trauma-informed services. I would underscore we need treatment resources and need more of them. It also remains very important that treatment is trauma-informed and that states and communities turn attention to Adverse Childhood Experiences (ACEs).

C4CJ note: Dr. Warren talked about a recent investment of $1.5 million in TN around ACES - The Building Strong Brains: Tennessee ACEs Initiative. This initiative represents "a public-private partnership among the state of Tennessee, the ACE Awareness Foundation, and a growing list of partners across the state. All partners are committed to creating a new culture in Tennessee that focuses on preventing ACEs and toxic stress from damaging future generations and harming the state's prosperity."[4] TN's ACES work has its roots in a 2014 visit with and learning from the Philadelphia ACE Task Force (*Philadelphia ACE Task Force charts its future while lending support to nascent city initiatives in Memphis and Pittsburgh*).[5] This July, TN released a funding announcement (for up to 20 projects) for "innovative projects….to prevent, mitigate or help persons recover from adverse childhood experiences and promote the health and prosperity of Tennessee citizens."[6]

Question: What about the Finnegan Score instead of blood draw or screen of meconium and incorporating the score into the plan of safe care?

LR: I like the Finnegan Score, but think you need as much information as possible. The Finnegan Score is used in many NICUs and probably is the standard of care. The challenge with trying to pull NAS into any newborn screening law is that it requires a test (e.g., blood, urine or meconium). DOH is still exploring what is the best practice for screening and to do some with a holistic approach.

MW: If we think about screening babies the Finnegan Score is a well published and validated tool, but still recognize it is a subjective test. That doesn't mean it is a bad test, but we do need to make sure that all people using are trained. Not all babies are going to develop full blown withdrawal symptoms so I always stress that we need to think about approach to screening the moms as well and doing such screening universally. States need to consider and address the babies who do not develop withdrawal in hospital and the mother has not been screened and so the mom and the baby are not on anyone's radar. Those are the babies and moms we should be work to build that safety net – a safety net that is so broad and so tight in a non-punitive way.

Question: The participant talked about how to prevent prescription opioids from getting into homes and how to do it in a reasonable way.

LR: Spot on. I am an admitting officer from the emergency room and sometimes discharging and it is amazing what can be written for upon discharge. She noted that, until recently, there has been limited guidance for medical professionals about prescribing. PA is trying to turn the tide on that and advancing what appropriate prescribing look likes. She discussed the prescribing guidelines and also PA's Prescription Drug Monitoring Program, which is currently a voluntary process by which a medical professional can check the database before they write a prescription for a controlled substance.

C4CJ note: Additional information about PA's Prescription Drug Monitoring Program (PA PDMP) can be found at http://www.health.pa.gov/Your-Department-of-Health/Offices%20and%20Bureaus/PaPrescriptionDrugMonitoringProgram/Pages/home.aspx#.V-GkK2HD9-Q

[4]https://www.tn.gov/assets/entities/dcs/attachments/Building_Strong_Brains,_OVERVIEW__MISSION_6.10.16.pdf
[5] http://www.acesconnection.com/blog/philadelphia-ace-task-force-charts-its-future-while-lending-support-to-nascent-city-initiatives-in-memphis-and-pittsburgh
[6] https://www.tn.gov/assets/entities/dcs/attachments/ACEs_Announcement_of_Funding_7-7-2016.pdf

Prescribing Guidelines, including those related to pregnant women, developed by the PA DOH and the PA Medical Society can be found at https://www.pamedsoc.org/Pages/Article-Detail-Page.aspx?TermStoreId=ab8b8fe3-5cb2-4091-916b-64792bec3d05&TermSetId=a6d4659a-154c-4b15-8266-4135869cd8f0&TermId=257806a9-5363-4650-ad81-c4b268755993&UrlSuffix=DownloadPAOpioidGuidelines

Question: There was an observation about the effectiveness of home visiting, but also that in Pennsylvania "only 4 percent of high risk population has access to evidence-based home visiting services."

LR: For PA DOH we are very big on nurse home visiting programs they are some of the evidence-based strategies that work and HRSA is all about evidence-based strategies that work. Home visiting works, there is evidence that shows its works. PA DOH is committed to continuing to grow even as the state faces funding crunches, constricted budgets. Our priority is to keep children and moms safe and to do so in a non-punitive and the most holistic way possible.

MW: TN used some of its federal Maternal Infant and Early Childhood Home Visiting (MIECHV) program dollars to create its Welcome Baby initiative. The state enlisted analysis of data that linked birth and death data to look at risk factors that might be predictive of infant death in the first year of life. It is not perfect but it does provide some insight that says if these things are present then there is a greater likelihood of death in the first year. Every baby (about 80,000 births a year) born in TN gets a Welcome Baby packet. Those babies rated as at medium or high risk then also get either an outreach call or visit. The program to reach those families, who may be most vulnerable, is entirely voluntary. TN is looking to apply for some MIECHV innovation funding to specifically address NAS.

C4CJ note: Here is a link to TN's Welcome Baby resources - https://www.tn.gov/health/article/welcome-baby

Question: Has there been consideration about NAS as the prime indicator especially since there is not a test for NAS? The speaker noted that the Finnegan Score is highly subjective. There needs to be extensive on-going reliability training and hospitals are starting to do more on that front, but prior to the recent focus on the opioid epidemic, it wasn't happening. Another challenge is that may only be called NAS if the baby needs to be treated so variability in how NAS is diagnosed. It will be important for states to be attentive to the wide room for error both with regard to false positives and false negatives.

MW: I would offer this single take home from Tennessee – it is critical how you message and frame the conversation. NAS as the indicator can be challenging when individuals see the video of a very irritable and rapidly shaking baby that invokes an emotional response that could lead you down a dangerous path. Of the 80,000 births in TN some subset are going to be substance-exposed and then some sub-set of those exposed infants will be affected. There is an exposure that is far bigger than opioids and seldom discussed and that is to tobacco – a very legal substance with well documented impact and consequences from exposure. There is limited research to inform about what happens to the NAS babies long-term. States need to think and move upstream to exposures beyond opioid (they are the substance de jour). We may crack down on the supply of opioids, but if we don't address and prevent the underlying issue of substance use disorder; then there will be another drug that fills that gap.

Question: How can we improve and be attentive to our language particularly related to illegal and legal drug use? Need to understand appropriate prescription drug use, including pain management and treatment for opioid use disorder (e.g., Methadone), and how that should inform whether a plan of safe care is developed at all and what it then looks like. The speaker noted the importance of ensuring that the development of the plan of safe care is done in a way that can differentiate for the

different life experiences (and substance use) of the mother, including those mothers who are compliant with treatment and are prepared/able to parent in a responsive nurturing environment.

LR: Important to cast a wide net and so yes some mothers are being appropriately treated for pain, but babies will still be exposed. Part of this is about education. The conversation with moms and moms to be about risk factors in taking certain prescriptions and help them know the supports available to them.

MW: In terms of reframing, may want to consider framing that underscores that addiction as a chronic relapsing disease. Think about/offer an example about the pregnant woman or postpartum mother with diabetes. If she is not compliant with managing her disease, no one automatically calls child protection. Need to remember and build solutions that recognize that people will come in and out of recovery.