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August 15th Initial "Solutions"

Respond to the March 30, 2016 request of Governor Wolf and legislative leaders to create a Task Force specific to children and the drug crisis

On March 30th, Pennsylvania's Center for Children's Justice (C4CJ) along with diverse allies dedicated to improving the safety, health and overall well-being of children impacted by parental substance use disorders called on Governor Tom Wolf and leaders of the General Assembly to establish a Task Force charged with identifying specific strategies to:

1. Prioritize prevention of substance-exposed infants,
2. Improve outcomes for pregnant and parenting women striving to recover from addiction;
3. Promote the health, safety and permanency of substance-exposed infants and other young; and children at-risk of child abuse and neglect or placement in foster care due to parental alcohol and drug use

Together we also are dedicated to increasing access to and reliance on reliable data and research to drive decision-making across systems (e.g., public health, substance abuse treatment, child welfare).

To date, C4CJ has received no response from legislative leaders. C4CJ and its allies did have a meeting with members of Governor Wolf's Cabinet on June 2nd.

Since the March request, there have been increasing number of moving parts related to state policy as well as Congressional action. The pace and scope of the policy decisions in Pennsylvania and Congress have the potential to undermine well-intentioned, yet quite disjointed, efforts to address the unrelenting prescription opioid and heroin epidemic.

Among the moving parts that require us to be on guard for connecting the dots:

- Convening a special legislative session on opioids leading to hearings all across the Commonwealth this summer.
- Establishing "a task force on access to addiction treatment through health plans and other resources" within PA's Department of Drug and Alcohol Programs (DDAP)[1] House Resolution 590 was adopted by the Pennsylvania House of Representatives in May. DDAP has announced the

[1] http://www.legis.state.pa.us/cfdocs/billInfo/billInfo.cfm?sYear=2015&sInd=0&body=H&type=R&bn=0590

members of the Task Force, is planning on convening a series of public hearings this fall, and has invited public comments toward informing a report and recommendations that will be submitted to the General Assembly in May 2017.[2]

- Directing the Joint State Government Commission (JSCG) "to establish an advisory committee to study issues relating to the need for, availability of and access to effective drug addiction treatment in this Commonwealth."[3] JSGC has identified and initially convened an advisory committee as required by the adoption of Senate Resolution 267.[4]
- Developing the Commonwealth's Annual Progress and Services Report (APSR), as required by the Administration for Children and Families (ACF). As part of this APSR, ACF directed states to offer specifics about the policy and practices related to substance-exposed infants subject to referrals to the child welfare agency and the development of a plan of safe care. Staff for Governor Wolf have indicated that the APSR "includes language that DHS believes safe plans of care require partnership and collaboration across systems to meet children's needs and to ensure families receive necessary services. It also notes that we will convene a stakeholder group including other state agencies and those outside state government to discuss how best to implement safe plans of care for substance-exposed newborns and develop a more comprehensive plan. Policy guidance will be issued as a result of the stakeholder engagement."
- Issuing Prescribing Guidelines related to pregnant and postpartum women.[5]
- Applying for a competitive Two –Generation Strategies Funding/Technical Assistance (TA) initiative through the National Governors Association (NGA) Center for Best Practices and the Center for Law and Social Policy (CLASP). If successful, Pennsylvania would receive up to $100,000 (over two years), technical assistance and peer support. PA's overall proposal framed as a "No wrong door approach to human services." If successful, PA would fund two pilots to develop "a family's needs assessment and checklist" utilized at entry points for human services. PA also sought to TA to "ensure appropriate services to infants with neonatal abstinence syndrome and their families.

Beyond these recent efforts, Pennsylvania has an existing Fetal Alcohol Spectrum Disorders (FASD) Task Force through the Department of Drug and Alcohol Programs (DDAP). The Task Force meets quarterly and has developed a statewide plan focused on awareness, education, prevention and treatment of FASD.

Also, as part of PA's Children's Roundtable Initiative, a Drug and Alcohol Workgroup was created in May 2013. This state-level workgroup "was tasked with exploring the issues of substance use and abuse and its impact on children and families within the dependency system and making best practice recommendations."[6] For two years, the Workgroup has enlisted the assistance and in-depth technical assistance from the National Center on Substance Abuse and Child Welfare (NCSACW). This technical assistance was particularly focused on eight counties: Allegheny, Clinton, Cumberland, Lackawanna, Lehigh, Lycoming, Monroe, and Venango. The D&A Workgroup has issued three separate reports and series of recommendations.[7]

[2] http://www.media.pa.gov/pages/DDAP_details.aspx?newsid=39
[3] http://www.legis.state.pa.us/cfdocs/billInfo/billInfo.cfm?sYear=2015&sInd=0&body=S&type=R&bn=0267
[4] http://jsg.legis.state.pa.us/ongoing-projects.cfm?JSOP_ONG_PROJ_ID=57
[5] http://www.health.pa.gov/My%20Health/Diseases%20and%20Conditions/A-D/Documents/PA%20Guidelines,%20on%20Obstetrics%20_Gynogology.pdf
[6] http://www.ocfcpacourts.us/childrens-roundtable-initiative/state-roundtable-workgroupscommittees/drug-and-alcohol
[7] http://www.ocfcpacourts.us/childrens-roundtable-initiative/state-roundtable-workgroupscommittees/drug-and-alcohol/state-roundtable-reports

Congress has also enacted the Comprehensive Addiction and Recovery Act (CARA) that included the Infant Plan of Safe Care Improvement Act crafted by United States Senator Bob Casey, Jr. and Pennsylvania Congressman Lou Barletta.

Outside of Pennsylvania, Republican Governor Charlie Baker recently agreed to a budget bill establishing "an interagency task force on newborns with neonatal abstinence syndrome and substance-exposed newborns charged with developing a statewide plan to collect data, develop outcome goals, and ensure that quality service is delivered to these newborns."[8] Other states have also acted to elevate the needs of and agenda for substance-exposed infants:

- **Colorado:** The General Assembly created the Substance Abuse Trend and Response Task Force in 2013 to continue the work of the State Methamphetamine Task Force. The Attorney General leads the 28-member Task Force.[9] There are three subcommittees including The Substance-Exposed Newborns Steering Committee. This subcommittee "addresses a variety of issues regarding the screening for and identification of drug-exposed infants and the connection to substance abuse treatment services for pregnant and post-partum women."
- **Florida:** With leadership from the Attorney General and other state leaders, Florida created a Statewide Task Force on Prescription Drug Abuse and Newborns in 2013. That same year the state launched a new website, BornDrugFreeFL.com.
- **North Dakota:** Through statute in 2015, "the task force on substance exposed newborns" was created for the purpose of researching the impact of substance abuse and neonatal withdrawal syndrome, evaluating effective strategies for treatment and prevention, and providing policy recommendations."[10]

Require reliable, timely and county-specific data on Neonatal Abstinence Syndrome (NAS) to inform policy and practice.

On September 3, 2015, Pennsylvania's Center for Children's Justice (C4CJ) filed a Right to Know (RTK) request with the Pennsylvania Department of Human Services (PA DHS) seeking multi-year data about the incidence of Neonatal Abstinence Syndrome (NAS) as well as data about the length of stay for infants diagnosed with NAS and the costs associated with care in a neonatal intensive care unit (NICU). The denial of that RTK request provided a powerful illustration of the gaps in understanding the scope of the challenges (and opportunities for prevention and intervention) associated with NAS in the Commonwealth.

PA DHS did work with C4CJ to produce NAS data for infants born onto Medicaid between 2010 and 2014.

That data revealed a near doubling of infants born onto Medicaid and diagnosed with NAS between 2010 and 2014 – startling yet incomplete numbers!

Ultimately it took nearly 4 months to obtain this data. While the data obtained was still important, it was also stale in its overall impact and relevancy given the dynamics of the unrelenting prescription opioid and heroin epidemic.

There are lessons to be learned from other states about how data is effectively informing policy and permitting measurement of outcomes (positive or troubling).

[8] http://www.lexology.com/library/detail.aspx?g=847c673f-4484-4a30-af45-49d05497df78
[9] http://coag.gov/SATF
[10] http://www.legis.nd.gov/assembly/64-2015/documents/15-1009-07000.pdf#page=1

In 2012, the Tennessee Department of Health added Neonatal Abstinence Syndrome (NAS) to the list of Reportable Diseases and Events with an effective date of January 1, 2013.[11] At the time, TN was relying on hospital discharge data related to the incidence of NAS. Reliance on this data set, was noted as creating a "lag time in reporting" as well as hindering access to "timely data on which to inform policy and program efforts."

In announcing the decision, the TN Health Commissioner wrote that the state had "seen a nearly ten-fold rise in the incidence of babies born with Neonatal Abstinence Syndrome in Tennessee." He continued, "Tennessee estimates suggest that the care of these infants may exceed $40,000 throughout the first year of life, compared with costs closer to $4,300 for an otherwise healthy infant born at a normal birth weight." He further wrote, "NAS also places a tremendous burden on the hospitals that provide care for these infants and the insurance payors who cover the costs of such hospitalizations, as well as the primary care providers who provide ongoing care in these often heart-wrenching cases. Costs to Medicaid (TennCare) alone exceeded $22 million in 2010."

TN issues weekly, monthly and annual NAS Surveillance Reports. The March 2016 update included these highlights[12]:

- "203 cases of Neonatal Abstinence Syndrome (NAS) have been reported since January 1, 2016
- In the majority of NAS cases (82.7%), at least one of the substances causing NAS was prescribed to the mother by a health care provider.
- The highest rates of NAS in 2016 have occurred in Sullivan County and the Northeast region."

Earlier this year, National Public Radio's All Things Consider examined the "scant data" that exists related to NAS (*A Crisis With Scant Data: States Move To Count Drug-Dependent Babies*).[13] In this NPR report prepared by WITF's Ben Allen, Dr. Warren cited that the data collection in TN "shattered stereotypes." Warren said, "I think sometimes there's a tendency to say these are just those moms who are using illicit drugs or buying those drugs on the street….but what the surveillance system has actually allowed us to see is that — in the majority of our cases — Mom is getting at least one substance that is prescribed to her by a health care provider."

In response to the NPR report, Pennsylvania officials announced that beginning July 1st the Pennsylvania Department of Health "plan to start collecting data about all babies who are born dependent on opioids." DOH officials told NPR's Ben Allen that the system was still "being developed" but that NAS would be included on the state's list of reportable diseases. There are currently 74 reportable diseases in the Commonwealth and NAS is not yet listed as among them.[14]

Other states are adopting public health surveillance approaches to inform NAS prevention and intervention strategies including:

- **Florida:** NAS became a mandatory reportable condition in 2014 following a recommendation from the state's Task Force on Prescription Drug Abuse and Newborns.[15]

[11] https://www.tn.gov/assets/entities/health/attachments/DreyzehnerLetterNASReportable_112912.pdf
[12] https://www.tn.gov/assets/entities/health/attachments/March_2016_-_NAS_Monthly_Update.pdf
[13] http://www.npr.org/sections/health-shots/2016/03/28/471308462/a-crisis-with-scant-data-states-move-to-count-drug-dependent-babies
[14] http://www.health.pa.gov/Your-Department-of-Health/Offices%20and%20Bureaus/epidemiology/Pages/Reportable-Diseases.aspx#.V7Gt22HD9-Q
[15] http://myfloridalegal.com/webfiles.nsf/WF/RMAS-9GUKBJ/$file/Progress-Report-Online-2014.pdf

- **Georgia:** Effective January 2016, NAS must be reported to the Georgia Department of Public Health.[16] State officials made NAS reportable in order to gather information that will help the state "to develop policies and programs aimed at reducing the number of babies who are born with NAS."
- **Kentucky:** State statute requires that "all cases of neonatal abstinence syndrome (NAS) diagnosed among Kentucky resident births shall be reported to the Kentucky Department for Public Health by the facility where NAS is diagnosed." Between August 2015 and July 2015, the state received "1,649 reports to Public Health." There were 1,234 unduplicated cases or "over 100 new cases of NAS in infants born each month in Kentucky."[17] In terms of the type of exposure the infant experienced, the KY data reveals "Of the mothers of NAS babies, 68% were reported to have prescriptions for the drug used. Close to half (49.8%) of the mothers were prescribed a medication as treatment for addiction, 14.1% were on a supervised pain therapy program, and 4.9% had prescriptions to treat a psychiatric or neurological condition prior to delivery."
- **Ohio:** Enacted in 2014, Ohio statute requires that "Each maternity unit, newborn care nursery, and maternity home shall report to the department of health the number of newborns born to residents of this state in the unit, nursery, or home during the preceding calendar quarter that were diagnosed as opioid dependent at birth. The reports shall be submitted not later than thirty days after the end of each quarter and shall not include any patient-identifying information."[18] Ohio is to issue an annual report based on the hospital discharge data shared about NAS.

Urge Congress to send the Family First Prevention Services Act to the President's desk. States require this legislation (and the redirected resources) to develop and monitor effective Plans of Safe Care.

Congress and President Obama worked together to ensure the Comprehensive Addiction and Recovery Act (CARA) became law last month.

Congress included The Infant Plan of Safe Care Improvement Act (S.2687/H.R. 4843) within CARA. S. 2687 was sponsored by United States Senator Bob Casey, Jr. and H.R. 4843 was sponsored by Pennsylvania Congressman Lou Barletta. The Plan of Safe legislation included in CARA:

- Amends the federal Child Abuse Prevention and Treatment Act (CAPTA)
- Requires federal agencies to issue guidance about best practices for development of Plans of Safe Care clarifying that such plans are to be developed for the baby in withdrawal, including if the withdrawal resulted from a drug that was legal and taken as prescribed by a medical provider.
- Enhances data collection/reporting on number of substance-exposed infants; and
- Strengthens oversight by HHS of state plans and actions on behalf of substance-exposed infants.

The specific change to CAPTA is outlined below:

(ii) policies and procedures (including appropriate referrals to child protection service systems and for other appropriate services) to address the needs of infants born with and identified as being affected by [illegal] substance abuse or withdrawal symptoms resulting from prenatal drug exposure, or a Fetal Alcohol Spectrum Disorder, including a requirement that health care providers involved in the delivery or care of such infants notify the child protective services system of the occurrence of such condition in such infants, except that such notification shall not be construed to—

(I) establish a definition under Federal law of what constitutes child abuse or neglect; or

[16] https://dph.georgia.gov/NAS

[17] http://chfs.ky.gov/NR/rdonlyres/40B04792-10AC-490C-89D0-881ED920BAD6/0/2016AnnualMeetingPreliminaryProgram.pdf

[18] http://codes.ohio.gov/orc/3711.30

(II) require prosecution for any illegal action;

(iii) the development of a plan of safe care for the infant born and identified as being affected by [illegal] substance abuse or withdrawal symptoms, or a Fetal Alcohol Spectrum Disorder **TO ENSURE THE SAFETY AND WELL-BEING OF SUCH INFANT FOLLOWING RELEASE FROM THE CARE OF HEALTH CARE PROVIDERS, INCLUDING THROUGH**

(I) **ADDRESSING THE HEALTH AND SUBSTANCE USE DISORDER TREATMENT NEEDS OF THE INFANT AND AFFECTED FAMILY OR CAREGIVER; AND**

(II) **THE DEVELOPMENT AND IMPLEMENTATION BY THE STATE OF MONITORING SYSTEMS REGARDING THE IMPLEMENTATION OF SUCH PLANS TO DETERMINE WHETHER AND IN WHAT MANNER LOCAL ENTITIES ARE PROVIDING, IN ACCORDANCE WITH STATE REQUIREMENTS, REFERRALS TO AND DELIVERY OF APPROPRIATE SERVICES FOR THE INFANT AND AFFECTED FAMILY OR CAREGIVER.**

While CARA got finalized, a much needed and related piece of legislation stalled after the United States Senate failed to follow the (unanimous) lead of the U.S. House of Representatives.

The Family First Prevention Services Act along with CARA provide incentive for states to make decisions that are intentional and impactful across a number of federal statutes and funding streams (e.g., Child Abuse Prevention and Treatment Act and the Social Security Act Titles IV-B and IV-E).

Under present federal law and practice, Title IV-E dollars match state dollars to pay for services that are essentially related to foster care or adoption related services. Title IV-E dollars can only pay for services to eligible child with eligibility linked to the old Aid to Families with Dependent Children (AFDC) that went away with 1996 federal welfare reform. In FY 2016, Title IV-E funding was about $4.7 billion.

Meanwhile, Title IV-B funding, which is more flexible and directed toward family support/preservation was approximately $355 million.

By contrast, Child Abuse Prevention and Treatment Act (CAPTA) was about $26 million in FY 2016.

The Family First legislation shifts the dynamic (and financing) toward prevention and effective earlier interventions. This legislation permits the use of federal funding toward often neglected and under-funded front-end services and supports that can prevent a child from being abused or placed in foster care. The legislation promotes a commitment to time-limited and evidence-based services on behalf of the child and the family, including services that are trauma-informed and can lessen the impact of mental health or substance abuse disorders. The legislation strengthens and continues the Regional Partnership Grants (RPGs) reinforcing that children who have a parent(s) with a substance use disorder require comprehensive and collaborative solutions.

Since 2003, Congress has recognized the added vulnerability of infants born exposed prenatally to drugs and alcohol. Congress, however, also understood that improving the outcomes for the infant required a preventive, not punitive, approach that assessed and responded to the needs of the infant and parents. More than a decade later, states and local communities have struggled to effectively respond to these infants and their families, in part because of conflicting federal guidance as well as insufficient available resources through the Child Abuse Prevention and Treatment Act (CAPTA).