COMMUNITY CATALYST

Massachusetts Working Group on Substance Exposed Newborns: A memo to summarize findings March 3, 2016

Introduction

The topic of substance use disorders has become an increasingly prominent public health issue, particularly as the opioid crisis has affected communities across the country. Lawmakers, public health professionals, advocates, families, and many others have come together in the wake of the crisis to identify strategies to reduce and prevent opioid addiction and overdose. The focus of this attention has largely been paid to the general adult population. However, this issue also affects another segment of the population that has received less attention: infants exposed to substances during pregnancy. The effects of pre-natal substance exposure have been well documented among substances such as alcohol and nicotine, but the opioid crisis has also given rise to increased prevalence of the specific symptoms associated with pre-natal opioid exposure, known as neonatal abstinence syndrome. Neonatal abstinence syndrome (NAS) "refers to the constellation of clinical findings associated with opioid withdrawal that usually manifests as neurological excitability, gastrointestinal dysfunction, and autonomic over-reactivity."[1] According to a 2015 study by the New England Journal of Medicine, the incidence of babies admitted to a Neonatal Intensive Care Unit (NICU) for NAS increased more than four-fold from 2004-2013.[2] In Massachusetts, the rate of babies born with NAS is greater than three times the national average, according to 2014 estimates based on hospital admission data.[3]

Effects experienced by substance-exposed newborns are wide-ranging, and can vary greatly depending on a number of factors, including the specific substances being used, duration of substance use, and intensity of substance use. Depending on the type of exposure, and other co-morbidities experienced by the parent, both the physical and cognitive development of the child may be hindered; consequences may include learning deficits, behavioral problems, and stunted growth.[4] Research has shown that the post-natal environment is critical to a child's development, and that many of the adverse effects experienced by substance-exposed newborns can be overcome through robust, coordinated care for the infant and their whole family.[5]

Massachusetts Working Group

The opioid epidemic has hit the New England region, and Massachusetts, particularly hard. Prompted by this epidemic, the children's health team at Community Catalyst convened a working group of individuals from across Massachusetts to consider the existing systems of care for substance-exposed newborns in general, including more traditional cases associated with alcohol, nicotine and other substances, as well as those that are a result of the opioid crisis. The working group has been meeting

[1] http://www.astho.org/prevention/nas-neonatal-abstinence-report/
[2] http://blogs.nejm.org/now/index.php/the-increasing-rate-of-neonatal-withdrawal/2015/05/27/
[3] https://www.bostonglobe.com/news/nation/2014/06/18/massachusetts-infants-born-with-opiates-system-three-times-national-rate-analysis-finds/wmfYrNDnWl8nposyOi9mCK/story.html
[4] http://pediatrics.aappublications.org/content/131/3/e1009.abstract
[5] http://www.astho.org/prevention/nas-neonatal-abstinence-report/

since July 2015, and has functioned primarily to: share information, promote coordination and alignment across various stakeholders, and identify potential areas for action and advocacy.

Lessons Learned

Due to the complex nature of this issue, affecting mothers, infants and families over their life course, many different stakeholders are involved in the care of families where one or more of its members are impacted by the adverse effects of a substance use disorder, whether that be a parent or a substance-exposed child. In Massachusetts, we quickly learned that there are a number of different initiatives and projects that have started with the goal of tackling this issue, utilizing a variety strategies and ideas, existing in different geographical locations, and organized and funded by different bodies that often do not have the opportunity to communicate or coordinate with one another. With so many players involved in the process, it is often difficult to know who is doing what, and what else is being done across the field. We have therefore used our working group as a space to promote coordination and alignment across different stakeholders. Thus far, we have heard from individuals in public health, child welfare, early intervention, providers and advocates in the mental health and substance use disorders spaces, children's hospitals and other health care institutions, and children's health advocates.

Through the working group, we've been able to identify a number of initiatives involved in caring for substance exposed newborns (including, but not limited to NAS) and their families. Though it is not an exhaustive list, we hope it serves as a starting point for further collaboration across the state:

- The Neonatal Quality Improvement Collaborative of Massachusetts is a project of providers across the state that was launched in 2013 with the goal of improving the care of infants impacted by NAS, and their families.
- The Massachusetts Bureau of Substance Abuse Services, within the Department of Public Health, is involved in several efforts and partnerships, including:
    - The Moms Do Care project, an effort announced last year that aims to expand treatment and improve care coordination for mothers with substance use disorders.
    - Development of a video series for families with maternal substance use issues.
    - Implementation of a webinar series for obstetricians on the issue.
    - Development of best practice guidelines and FAQs for providers serving pregnant women with substance use disorders.
- The Bureau of Family Health and Nutrition, also within the Department of Public Health, is engaged in a number of efforts with programs under their purview, such as:
    - The development of a workgroup to evaluate the capacity of the Early Intervention system to serve babies diagnosed with NAS, and their families.
    - The Women, Infants, and Children (WIC) Nutrition Program has been assessing how it meets the needs of clients dealing with substance use issues.
    - The Massachusetts Home Visiting Initiative is mapping out what services are available for this population, including making families (and especially women of reproductive age) with substance use disorders a priority population for programs that they fund.

- The MA Early Intervention (EI) program, within the Department of Public Health, is a statewide service available to families with children up to three years of age, and serves as a valuable tool for addressing SEN through a two-generation frame (see more information below on the 2-generation lens). This service is available to families with children up to three years of age whose development may be impaired, either due to identified disabilities, or certain circumstances, such as parental substance use. Children may be referred to EI from a number of sources, including the Department of Children and Families, hospitals, and pediatricians. Early Intervention services are provided by professionals, are tailored to the child's needs, and may include assistance around cognitive development, motor skills, behavior, and parenting skills. Currently, children who are officially diagnosed with NAS are automatically eligible for EI for one year.
- The Health Policy Commission will be releasing its request for proposals soon to build on the DPH Moms Do Care initiative, as well as developing an inpatient Quality Improvement package related to NAS.
- The Massachusetts Perinatal Quality Collaborative, in collaboration with BSAS and MCPAP for Moms, is working on developing a toolkit for medical providers, especially prenatal providers, to use when working with pregnant women with substance use disorders.
- The Institute for Health and Recovery has several programs centered around families with substance use disorders, including providing training and coordination to the Moms Do Care project mentioned previously.
- Jewish Family and Children's Services has a project called NESST (Newborns Exposed to Substances: Treatment and Therapy), which is currently the only home visiting program in the state specifically serving substance exposed newborns and their families.
- The Boston Medical Center runs Project R.E.S.P.E.C.T. for the treatment of addiction during pregnancy.
- The recently passed "Protecting Our Infants Act of 2015" is a federal law that requires the US Department of Health and Human Services (HHS) to provide new guidelines and steps around data collection by state governments to better understand and analyze NAS.

Through discussion and sharing, the working group has also identified certain positions to guide work on NAS and other forms of substance exposure among newborns, including:

- It is critically important that we address this issue through a **two-generation lens**. That is, treating the mother and child as a unit, or dyad, rather than considering the needs of mother and child separately. Approaching the issue with a two-generation lens provides the best opportunity to ensure positive outcomes for the child, as well as the mother, over the life course of both.
- **Coordination and communication** to ensure robust family-centered care remains one of the biggest challenges in this area, and manifests at the state and family levels. Massachusetts currently lacks a unifying public health framework to approach families who are dealing with substance use disorder among parents, and substance exposure among children. A number of different state agencies and providers work with these families, and without an overarching

framework, many efforts to care for families happen in siloes. In addition, without mechanisms for data collection, tracking of families, appropriate referrals and coordination of care across there is increased risk of loss to follow-up. Systematic state-wide protocols could support coordination and communication across agencies and providers, which would not only ensure that efforts across the state are not needlessly duplicated, but more importantly, would help ensure warm hand-offs between providers so families receive all of the available services they need over time.

Next Steps

In the coming months, this Massachusetts working group has agreed to continue to coordinate through quarterly conference calls. Individual partners on the working group will continue to explore areas of opportunity to advance this work and will use our email list and conference calls to continue to share and coordinate with the larger group. We will also continue to explore some of the unanswered questions summarized below.

One piece of this work that is currently moving is around Early Intervention for substance-exposed newborns. As mentioned earlier, Early Intervention (EI) is a valuable tool in assisting substance-exposed newborns and their families. Currently, children officially diagnosed with NAS are automatically eligible for one year of EI. However, NAS is a very specific diagnosis, and does not include newborns exposed to substances other than opiates. A proposal currently being proposed to the Department of Public Health by the Massachusetts Early Intervention Consortium would increase eligibility to 3 years for those children diagnosed with NAS, and potentially create an automatic eligibility for one year for newborns who have experienced adverse substance exposure of other types that do not currently give them automatic eligibility. Members of the working group are currently active on this issue and working to expand automatic eligibility. They are also coordinating with the Children's Health Access Coalition, a coalition of Health Care for All – MA, to explore additional administrative or legislative action.

Unanswered Questions

Over the course of the last few months, the working group has also uncovered a number of questions and potential priorities for the state that have yet to be addressed. Though not an exhaustive list, we have included some of these questions below as a starting point for ongoing discussion. We encourage all partners and stakeholders who are thinking about how to improve systems for substance exposed newborns to consider these questions as a starting point for inquiry, education and potential advocacy.

How can different treatment and service providers communicate more effectively? One of the lessons learned from discussions was that with so many people involved in caring for a mother and child, coordination is essential, but very difficult. It would greatly benefit both mothers and children if these different entities had more systematic and regular communication to coordinate family-centric care. Developing a state-wide protocol and supports to guide the sharing of information between different parties working with the same family would create smoother and more seamless care, and robust, coordinated care across providers increases the likelihood of positive outcomes for the mother and child.

How can providers better gather and utilize data? The implementation of communication and information-sharing protocols also raises questions around the challenges of collecting, sharing and tracking appropriate data. Because substance exposed newborns and their family members are cared for and treated by different organizations and agencies, proper tracking and recording all activity has been identified as a challenge. This is a critical component of monitoring progress, especially among infants, in which change can happen at a rapid pace.

How can care for mothers incorporate preventative methods to reduce the risk of substance-exposure among newborns? With a two-generation framework in mind, preventative care for women struggling with substance use disorder during the pre-, post-, and inter-natal periods is extremely important. This includes the use of evidence-based screening tools, such as SBIRT – Screening, Brief Intervention, and Referral to Treatment, that are tailored for women of child-bearing age. However, these types of tools have yet to be incorporated systematically throughout the state. There are many creative solutions to integrating preventative care for mothers struggling with substance use disorder. Just a few that have been raised at the working group, include ensuring that codes for maternal SBIRT are turned on in Medicaid, working with clinicians, treatment centers and other community-based service providers to incorporate SBIRT or other evidence-based screening protocols, and working with treatment centers to meaningfully incorporate family planning into their treatment for women of child-bearing age, where these services are not already being implemented.

How can promising and best practices be sustained on a long-term basis? In 2011, the Massachusetts Health Policy Forum developed a policy brief and held a conference to review substance exposure among newborns and its impact throughout a lifespan. Findings from this review and conference indicated that the largest barriers to a robust continuum of care for substance exposed newborns and their families is the adoption and scale-up of existing best practices. Resources have been spent and continue to be invested to test and refine these best practices. However it still remains unclear how initiatives can be sustained and expanded. As this work moves forward, it will require carefully looking at funding streams and sources to identify ways in which treatment for substance-exposed newborns can be made easily accessible on a larger scale. In the coming months, please look out for a more in-depth policy brief from Community Catalyst that will identify additional opportunities for prevention.

To learn more about this working group, please reach out to Gabrielle Orbaek White at gorbaekwhite@communitycatalyst.org or (617) 275-2831.