

# Community Report



## In Her Words: Opioid Use Disorder and Pregnancy



**McMillenHealth**  
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HEALTH FOUNDATION

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## In Her Words: Opioid Use Disorder and Pregnancy Prepared by: Holli Seabury, EdD

This project began when McMillen Health was approached by Fort Wayne pediatrician, Dr. Tony GiaQuinta, 2018.2019 President of the Indiana Association of Pediatricians. Dr. GiaQuinta asked us to collaborate on developing educational materials for women with opioid use disorder (OUD). His goal was to have high-quality educational materials for pregnant women and mothers of infants and young children.

When educational interventions are being developed, often the critical voice and input from the end user, in this case women with OUD, is missing. It was of the utmost importance to McMillen Health that before any educational materials were developed, women would be heard. We wanted to try to understand their experiences, what type of education they felt they needed, how they wanted it delivered, and who they wanted to deliver it. Moving forward, the plan is that the women who were interviewed for this project will form an advisory group. This group will help us determine topics and how to best present education.

While we wanted women's input, we also wanted the input from the professionals who work with these women, to identify where they felt there was a deficit in resources. The information from the interviews will be used to propose a design for an educational platform to meet the needs of parents and professionals. The goal of this education will be to help women and their partners parent to the best of their abilities and to help children exposed to opioids in utero reach their full potential.

## Definitions

**Addiction:** A primary, chronic, neurobiologic disease with genetic, psychosocial, and environmental factors influencing its development and manifestations. Addiction is characterized by behaviors that include: impaired control over drug use; compulsive use; continued use despite harm; and cravings.

**Buprenorphine:** A semisynthetic opioid to control moderate to severe pain and to treat opioid use disorder. Brand names include: Bunavail, Buprenex, Butrans, Subutex, Suboxone, and Zubsolv. The most recognizable medication-assisted treatment are Subutex and Suboxone (during pregnancy Subutex is recommended).

**Dual Diagnosis:** Describes patients with both mental illness and substance use disorder.

**Illicit:** Illegal or unlawful.

**Medication-Assisted Treatment:** Medication-assisted treatment (MAT), including opioid treatment programs, combines behavioral therapy and medications to treat substance use disorders.

**Methadone:** A synthetic opioid medication used to reduce withdrawal and post-acute withdrawal symptoms and is often used as a mid- to long-term opioid use disorder medication for helping stabilize and facilitate recovery among those suffering from opioid use disorders.

**Neonatal Abstinence Syndrome:** Neonatal Abstinence Syndrome (NAS) describes the lexicon of symptoms that may be suffered by newborns who have been exposed to opioids in utero. Infants affected by NAS typically show a number of neurological symptoms and behaviors such as tremors, screaming, seizures, breathing problems, and poor feeding. These infants are also more likely to have a low birthweight.

**Opioid:** A family of drugs used therapeutically to treat pain, that may also produce a sensation of euphoria (a “high”) and are naturally derived from the opium poppy plant (e.g., morphine and opium) or synthetically or semi-synthetically produced in a lab to act like an opiate (e.g., methadone and oxycodone). Chronic repeated use of opioids can lead to tolerance, physical dependence, and addiction.

**Polysubstance Use:** Polysubstance use involves the consumption of more than one substance at once. Although polysubstance abuse often refers to abuse of multiple illicit drugs, it’s also inclusive of prescription medications used in nonmedical circumstances.

**Recovery:** The process of improved physical, psychological, and social well-being and health after having suffered from a substance use disorder.

**Substance Use Disorder:** A medical condition in which the use of one or more substances leads to a clinically significant impairment or distress. Substance use disorders are characterized by an array of mental, physical, and behavioral symptoms that may cause problems related to loss of control, strain to one’s interpersonal life, hazardous use, tolerance, and withdrawal.

**Opioid Use Disorder:** Opioid use disorder (OUD) is defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM–5) as a problematic pattern of opioid use leading to clinically significant impairment or distress.

From the Recovery Research Institute’s Addictionary.

## The Problem

Opioid misuse is a national public health emergency; in Indiana opioid overdoses increased by over 400% from 2006 to 2016 and another 50% from 2016 to 2017 (CDC, 2018). The increase in opioid use has led to a devastating side-effect: pregnant women who are using opioids who give birth to babies born with Neonatal Abstinence Syndrome. When pregnant women are using opioids, whether through a prescription, a medication-assisted treatment program, or through illicit use, the opioids pass easily from the mother's bloodstream and through the fetal blood-brain barrier. Birth brings a fast end to the influx of opioids to the baby, which can cause symptoms of withdrawal called Neonatal Abstinence Syndrome (NAS). Infants affected by NAS typically show a number of neurological symptoms and behaviors such as tremors, screaming, seizures, breathing problems, and poor feeding. These infants are also more likely to have a low birthweight. NAS symptoms occur in 75-90% of infants exposed to opioids in utero (Hudak & Tan, 2012).



**This report uses the more commonly known term of Neonatal Abstinence Syndrome (NAS). This term was developed in the 1970s to describe a constellation of withdrawal symptoms in newborns. However, withdrawal from opioids has a specific set of symptoms. Recently, the term Neonatal Opioid Withdrawal Syndrome (NOWS) has been developed and will most likely take the place of NAS when describing newborns who have been exposed to opioids in utero (Sutter, Leeman, & Hsi, 2014).**

Every 15 minutes in the US a baby is born who will experience withdrawal symptoms from being exposed to opioids in utero. The rate of infants diagnosed with NAS increased 433% in the years from 2004 to 2014 (Winkelman et al., 2018). Indiana has a rate of NAS that is about 30% higher than the national average: 15.7% of all Indiana babies test positive for opioids (CDC, 2018). Since testing all pregnant women for opioid use is not yet mandatory in Indiana, many experts estimate that the true number of babies exposed to opioids is much higher. Many pregnant women with opioid use disorder (OUD) will not receive prenatal care because they fear incarceration or they did not realize they were pregnant (Howard, 2016). Pregnant women who have an OUD are often reticent to seek recovery treatment while pregnant because they fear their baby will be removed from their home by the Department of Child Services (DCS) or they will be harshly judged by their community (SAMSHA, 2009).

Nationwide, the average newborn with NAS symptoms will spend 16.9 days being monitored in the Neonatal Intensive Care Unit (NICU). Many are given morphine or phenobarbital injections to reduce their symptoms (Patrick et al., 2015). The financial cost of NAS is devastating, with the average hospital cost for a baby with NAS being \$66,700 as compared to \$3,500 for a healthy newborn. Predominately, mothers of babies affected by NAS are low income: 80% of babies with NAS are covered by Medicaid insurance (Patrick et al., 2015).

Rural communities have been hit harder by the opioid crisis, with NAS increasing at a rate 80% higher than in urban communities. Part of this increase is due to the dearth of treatment options in rural areas and the difficulties with transportation to treatment centers faced by rural mothers (Villapiano et al., 2017).

Fifty percent of the pregnancies in the US are unintended (Finer & Zolna, 2014). The high rate of unintended pregnancies is critical as between the years of 2012 to 2015, 27.7% of privately insured and 39.4% of Medicaid insured women of childbearing age (15-44) filled a prescription for an opioid each year (Ailes et al., 2015). Women are more likely to take opioids without a prescription to treat pain and also are more likely to use opioids to self-medicate for anxiety or other mental health issues (McHugh et al., 2013).

Medication-assisted treatment (MAT) for OUD has been available since the 1970s and is the recommended treatment for pregnant women. The goal of MAT is to reduce cravings and prevent illicit opioid use, as part of a comprehensive treatment plan. As compared to pregnant women with OUD who get no treatment, pregnant women on MAT attend more prenatal visits, have babies with higher birth weights, and have lower rates of neonatal death and growth restriction (Kandall, et al., 1977; Kaltenbach, Berghella, & Finnegan, 1998; Finnegan, 1991). The choice of medications used for MAT varies, based on a women's personal history. Buprenorphine is currently the medication of choice for pregnant women receiving MAT for the first time; methadone is often chosen if a women has had previous unsuccessful treatment attempts or is being treated for multi-substance abuse (Mozurkewich & Rayburn, 2014).

## Impact on Infants

As the opioid crisis is fairly recent, there is not a large body of research on the long-term effects on infants exposed to opioids in utero. The focus in the literature, and in educating parents, tends to be on the newborn's symptoms of NAS, and not on the potential long-term effects.

Infants exposed to opioids in utero are at higher risk of issues with behavior/cognition, vision, and motor skills (Ross et al., 2015). Studies have found babies born to women taking methadone (as part of a medication-assisted treatment) crawl and sit later than their peers (Logan, Paul, & Heller, 2011) and toddlers exposed to opioids in utero score lower than their peers on tests of memory, problem solving, and verbal communication (Maguire et al., 2016).



Pregnancy offers a unique opportunity for pregnant women to enter into treatment. The Regional Mental Health Coalition of Northeast Indiana (2019) recommends a medication-assisted treatment (MAT) for pregnant women since it has been shown to have a lower relapse rate. Relapse rates for women using medically assisted withdrawal can be up to 90% (American College of Obstetricians and Gynecologists, 2017). Methadone and buprenorphine may be used during pregnancy, although babies born to mothers using these medications are still at risk of having NAS symptoms. Both methadone and buprenorphine are also safe to use during breastfeeding.

A recent study found newborns with NAS are born with a significantly smaller average head circumference when compared to babies not exposed to opioids in utero (Towers et al., 2018). Centers for Disease Control (CDC) researchers tracking babies in Tennessee, one of the states hardest hit by the opioid crisis, found that in comparison to children who had not been exposed to opioids during pregnancy, children exposed to opioids in utero were:

- **44% more likely to be referred for evaluation of potential developmental delays;**
- **36% more likely to meet their state's criteria for educational disability;**
- **37% more likely to receive help with educational and developmental difficulties (Thompson, 2017).**

While many studies to date have shown concerning results, a weakness in the literature has been the lack of large, longitudinal studies. In June 2019, the largest longitudinal study of infants exposed to opioids in utero was released (Azvine, et al., 2019). Conducted at Boston Medical Center, the study began in 1998 and followed 8,509 mother-child pairs for 21 years. The data showed the impact of the opioid crisis with infants exposed to opioids in 2003 (the lowest point of the study) being 12.1 per 1,000 births to a high in 2012 of 63.1 per 1,000 births.

## The study showed infants exposed to opioids in utero had a significantly higher risk of:

- Preterm birth;
- Fetal growth restriction;
- Lack of expected physiological development.

## In childhood, exposure to opioids in utero was associated with:

- Conduct disorder;
- Emotional disturbance in preschoolers;
- Attention deficit/hyperactivity disorder in school age children.

Parents of a baby with NAS say education is their primary unmet need (Atwood et al., 2016). It is critical that intervention for mothers comes as soon as possible in their infant's life, ideally during pregnancy. Mothers and caregivers of an infant who has been exposed to opioids in utero want to understand how to best protect their baby during pregnancy, what to expect in relation to NAS symptoms immediately after birth, and what to expect throughout childhood in relation to developmental milestones.

Research on exposure to opioids in infants is often confounded by the low socio-economic status of many mothers, polysubstance use, and other social impacts. Larger studies need to be conducted, but some smaller studies have indicated babies exposed to opioids in utero may be at higher risk for serious birth defects of the baby's brain, spine, and heart, as well as preterm birth (Brogly et al., 2017; Broussard et al., 2011; Kellogg, Rose, & Harms, 2011).

The opioid crisis has also led to a staggering number of children who must be removed from the home; a 129% increase in the years between 2012 and 2015. Children removed from their home due to parental neglect have increased rates of mental and physical health problems, teen pregnancy, and delinquency (Quast, Storch, & Yampolskaya, 2018).

## Target Population:

The target population for this project was women who have routinely used prescription or illicit opioids during pregnancy or were enrolled in a medication-assisted treatment (MAT) program for opioid use disorder while pregnant. Nationwide, these women are typically in their 20s and are predominately low-income, with 80% enrolled in Medicaid. Our local population also fit these parameters. Nine of the mothers were referred by Sarah Turner, MD, who has specialized training in treating pregnant women with OUD. The tenth mother was referred by Healthier Moms and Babies, a home visiting program for at-risk pregnant women.

A secondary target population was the professionals working with these mothers. This includes physicians, home visitors, nurses, social workers, child protective services, court officers, recovery specialists, early interventionists and more.

## Interviews

Interviews with mothers lasted from 60 to 120 minutes and were conducted in the location of the woman's choice. Interviews followed a structured set of questions, but were conducted in a semi-informal manner. Interviews were recorded and transcribed by Rev, a professional transcription service. Interviews were coded to determine themes.

The goal of the interviews with mothers was to explore their experiences with pregnancy and birth as a woman with OUD. Often, their experiences did not match the experience the professionals interviewed felt their organization was providing. In qualitative research this is common; individuals having a shared experience may each perceive it very differently.

Women were asked about their history with opioid use and recovery and their experience with pregnancy and delivery. Interviews focused on their experience and the education they received and what education they would have liked to have received. The possibility of a new educational intervention being developed for pregnant women with OUD was discussed and women were asked about their ideal method of educational delivery. Most of the women (6) were having, or recently had, their first baby. The four women who were having babies which were not their first child had all relapsed between pregnancies.

Seventeen professionals who work in some capacity with pregnant women with OUD were also interviewed. A semi-structured set of questions was asked about their current experiences and what they would desire in an educational intervention. Interviews lasted from 60 to 120 minutes and were recorded and transcribed by Rev.

Interviews were conducted with ten women who were either pregnant or had given birth in the past year and had been diagnosed with OUD.

### Self-reported demographics are:

**Age Range:** 19-39

**Ethnicity:** White 9, African-American 1

**Pregnant:** 4

**First Baby:** 6

**Insurance:** Medicaid 8, Private Insurance 2

**Level of education:**

Some high school 1      High school graduate 7

Some college 2      College graduate 0



The women interviewed had varied paths to opioid use. Some developed an addiction after being prescribed an opioid for pain from an injury or for a medical condition. Most had a long history of substance abuse, usually starting in the teen years. The women who began abusing substances while they were very young typically had parents or siblings with substance use disorder. They also tended to be polysubstance users, mainly marijuana or cocaine. All the women in the study had a dual diagnosis of depression, anxiety, or another mental illness, in addition to their diagnosis of opioid use disorder.

*And that's usually how most people's addiction starts, is with a simple injury and they start to take more or they like the way it makes them feel so they take more. Mine started with my grandpa actually, he started giving me Narcos (for her back pain) when I was 18. And he used to give them to me for free. And I used to just go there to help him all the time and he'd just give them to me and I'd try to give them back but he'd be like, I see you're in pain.*

*- Valerie, pregnant with second baby*

Two of the women had been patients of physicians who have since been identified as unethically prescribing opioids and other medications.

*He was my family doctor during my pregnancy. So he had me on like Xanax, Ritalin, and Methadone for part of my pregnancy, and the other part of my pregnancy, he had me on Valium, Adderall, Percocet and Oxy's. But he told me that it was ....safe for the baby, and I believed him. And, I mean, look what happened?*

*- Tanya, mother of six, talking about how she lost custody of her children*

## Results

Several themes emerged from the interviews in regards to women's experiences with pregnancy and birth. The main themes were: (1) Pregnancy as a motivator for entering or staying in treatment and (2) the guilt and stigma surrounding OUD and MAT during pregnancy. Additional themes included the need for a support system; relapse after giving birth; feeling punished for being honest about OUD; fear and guilt about baby's withdrawal symptoms (or potential symptoms); concerns about Department of Child Services (DCS) involvement and the potential of losing custody of their baby; and the need for physicians who are trained to treat pregnant women with OUD.

### Pregnancy as a Motivator for Recovery

Seventy percent of the women interviewed were not in a treatment program when they became pregnant; pregnancy was the motivator for beginning MAT. All women interviewed were on MAT when they gave birth. Some mothers began MAT out of a desire to have a healthy baby and to be the best mother they could be.

*I'm a recovering addict. So, I'm not a selfish person and I like to say that, but when it came to drugs, I was very selfish and it took me a really long time to understand that. And then having her (her daughter) ... it's not about me anymore. It's all about her... And I probably would have been dead by now.... I'm like almost 99% sure I would've been dead.*

*- Clarissa, mother of five month old baby*

For other mothers, beginning MAT was driven by a fear of having their baby removed from their home because of their OUD. These mothers tended to have had past experience with DCS with their older children.

***I wish I didn't have to take methadone, but it has saved my life. I've gotten all my rights back to my other four kids that I had no rights to. Before I was seeing them like two hours once a month through the court. And now I get them every other weekend, and on Wednesdays like everybody else in the world.***

- Tanya, mother of 6

While the women who did not have a history of substance use tended to tell their physician about their opioid use and follow the MAT prescribed, women with a long history of substance abuse, who also had many friends with substance use disorder, tended to self-medicate before telling their physician about their opioid use.

***Honestly, I have a substance abuse problem and I had somebody that was getting the Subutex and I wanted to quit, but I didn't want to do it cold turkey because I went through this with my last baby. I was getting it illegally, obviously....because they gave me the Subutex with my last baby too. I wanted to see about getting back on that because it is worse this pregnancy than it was with my last pregnancy because I relapsed and when I relapsed, I relapsed hard. Then I found out I was pregnant. I've been clean since May (6 months of pregnancy). I haven't used any drugs or anything.***

- Meghan, pregnant with her fourth baby. Her older three children are in foster care, she was homeless when she discovered she was pregnant.

## **Stigma and Guilt**

Nine of the mothers were patients of Sarah Turner, MD, who has specialized training in pregnancy and OUD. Her patients report she supported them in starting or continuing MAT, emphasizing it was the healthiest choice for their baby. She also created a supportive environment for them in regards to MAT. Because they believed MAT was the healthiest and best choice for their baby, many mothers were surprised and hurt by the stigma they felt existed in regards to pregnant women and MAT.

***There was a lady at work who actually found out that I was on methadone. She was saying that I was having a drug baby and telling everybody....I get where they're coming from if they don't know the information and how it helps people (MAT)...they're just not educated about any of this. They just jump to conclusions right away. That's what I don't like, because people think that we're going to this methadone clinic and we're still getting high. I am not high. I can function. I still work. ....I still feel guilty, but I know that it was what was right for me and the baby at that time. Honestly, with my emotions, with how crazy they were being pregnant, if I wasn't on the methadone, being a recovering addict, I have no doubt in my mind that I would have used.***

- Brittany, mother of 4 month-old (has been on MAT two years)

***Being an addict does not define you, it's just a label. It's like saying that I have brown eyes, it's a part of you, it's not the sum of you. It's nothing to be celebrated nor feared, it's just something to be dealt with, or if it's something where you have to take Suboxone because it's medically assisted or whatever, you don't have to be ashamed of that. You are doing what's best for you, and people don't understand that.***

- Amy, mother of 12 month old, on MAT for ten years

Many women also faced stigma from pharmacy staff and medical providers. One mother describes taking her baby to the pharmacy with her to fill her Subutex prescription and her belief that they were trying to shame her because she had a baby and was on MAT.

*I had three people, like the pharmacy tech guy, like the head guy...One was literally holding my medicine (Subutex), it had been two days trying to get it. Then the head guy was.....while I was out on the floor (in front of other customers), asking me what medicines I was on (wanting me to say Subutex out loud), because they need to know, my insurance needed to know, blah blah blah. I was so embarrassed!....I started to get frustrated and ... and then I looked at him and...and I go, "This is fucking embarrassing." And he looked at me like I was crazy and right there, in my head, I was like, I just gave him what he wanted. He probably thinks I'm just some druggie...That was exactly what was going through my head and that upset me more. I was so upset, I cried, like literally, I went home and I cried the rest of the day.*



- Clarissa, mother of five month old baby

All of the women related at least one experience where they felt they were being shamed or stigmatized while their baby was in the hospital immediately after birth.

*When I had her, the nurses treated me different.... Not all of them, but there was a few. One of them actually told me, and I'll never forget it, she looked straight me and she said, "You're different from the rest." I had no idea what that meant, you know....I was like "What? What does that even mean?" I have a hard thing about confrontation...so I just didn't say anything and I talked to my mom about it and my mom was like "What the hell's that mean? Why did she even say that to you? She shouldn't say that to you." I'm like, "This has gotta be the medicine (MAT). I mean, I'm an addict..."*

- Clarissa, mother of five month old baby

*The first time that my husband went in there without me (the NICU), a nurse was telling him how it was my fault that our daughter was in there because I chose to be a drug addict and give my daughter drugs instead of to be clean during my pregnancy.*

- Tanya, mother of six

In addition to the judgement they felt from others, many of the mothers felt internal guilt about being on MAT while pregnant.

*It made me feel guilty for being on the methadone, and I think that's what I struggled with, being pregnant the entire time is that I felt like I was doing something wrong the entire time, even though I needed this right now, because if I didn't,*



***I could be doing all the other drugs that I was doing, you know? I was clean two years (on MAT). By the time I had him, I had been clean for two years. We still feel this big (holds up two fingers close together). Even though we're getting all this help, we still feel like a little ant, and all these people are stepping on us, and we have to just try to get through it, on top of being on the methadone, you know?***

*- Brittany, mother of four month old baby*

## **Support Systems**

Having a support system in place for birth was difficult to establish for most mothers. Those who had entered into addiction through a prescription, and had no family or friends with a history of substance abuse, were often too embarrassed to tell family or friends about their OUD and the NAS symptoms their baby might have.

***Just like only a handful of people in my family know that I go up there (to the methadone clinic). My boyfriend's family doesn't know I go up here. My mom knows and my sisters know. That's about it.***

*- Brittany, mother of four month old baby*

Those who had a long history of substance abuse found they lost their support system when they went into recovery because their friends, and sometimes their family and partner, were still abusing substances. Many of these women had alienated their families through years of substance abuse, and although they were in recovery, they had not been able to re-establish those relationships.

***When you've quit using everybody who you thought was your friends, when you're in recovery you don't hang out with them. You don't associate with them no more. Even if you were good friends you still have that connection with them (substance abuse) so it's hard to continue to be friends with them....At the beginning of it (recovery) there's no way I could hang out with somebody knowing they could get me dope. There's no way I could hang out with them.***

*- Meghan, pregnant with her fourth baby*

In talking about their experience in the hospital, many mothers talked about how difficult it was to get to the hospital to see their baby, especially if they had a limited support system. Most of the mothers had Caesarian sections and were released from the hospital before their baby was released. Because of their surgery they could not drive themselves to the hospital to see their baby and had to rely on a partner or support system to take them. If they had other young children at home that added an extra layer of difficulty in that they had to find childcare for their children. At the same time, because they were on MAT their baby would be tested for opioids, and would test positive. Several mothers had DCS involvement, which led them to feel they were being judged adversely if they could not come to the hospital every day to visit their newborn.

## **Relapse**

The four women who were not having their first baby had all relapsed between pregnancies. Pregnancy was a motivator to enter recovery, but after the baby was born they were not able to stay in recovery.

***Depression and starting to use again, and starting to use illegal drugs again, and a lot of it is because of depression, but some of it's just because of the physical changes in your body once you have a baby. But most of it I think is like you feel judged, you feel embarrassed, you feel stressed, really, really stressed.***

*- Sabrina, mother of 3, discussing her relapses between pregnancies*

The cost of treatment was also a determining factor for new mothers in staying on MAT.

*Now that I've had the baby, what I do as far as the methadone and stuff's not gonna affect him. So I don't know if I'm gonna be able to even continue that. I'm just gonna try to come off of it the best way that Dr. Turner and the other counselors and stuff that are gonna help me with that, and then just try to break totally away....The methadone is \$15 a day and I drive from almost 30 to 45 minutes away, so there's the gas too. Then bringing the baby. And I'm not judgmental about anybody that goes there, but when you take your kids, you have to leave them in the waiting area. The security guard is there. He's a really nice gentleman. But I don't want to leave my kid sitting out there in the waiting area with all these strange people. When I got pregnant it was dangerous for me to stop doing it. Everybody told me, so I went as much as I could and I was working also, so I could afford it. But now it's just ... It's either gonna be pay for the methadone clinic or buy formula or diapers or something.*

*- Bethany, mother of four week old baby*

*When my son was born, just because, and this is another thing, women that deal with addiction usually are dual-diagnosed, they deal with addiction and depression, and anxiety. So you are like three times more likely to deal with post-partum. So now you've got post-partum, which I did..... Now I look back and I know, well my hormones are all out of whack, I just had major trauma done to my body, I'm suffering from post-partum, and then I'm worried about all the Suboxone stuff on top of it.*

*- Amy, mother of 12 month old, she has been on MAT for ten years*

### **Being Punished for Honesty**

Many mothers expressed frustration at the feeling of being punished for their honesty about OUD. Many had friends with OUD who had not been honest with their medical provider while they were pregnant. If providers are not aware a baby was exposed to opioids in utero, there is a good chance the baby may leave the hospital before NAS symptoms are obvious. This allowed these friends to avoid potential DCS involvement. While it is dangerous for the baby to have NAS symptoms in the home environment, because of the chances of abuse, many of the mothers interviewed felt they should not have been honest about their OUD.

*I really do feel like I was punished for being honest. I know friends who use their whole pregnancy and nothing's happened. They bring their baby home and no (DCS) cases, no nothing.*

*- Meghan, pregnant with her fourth baby, older three children are in foster care*

*So it's like, not only is he in the NICU withdrawing, you got nurses looking at you crazy. I used cocaine in my pregnancy, God forbid, I went to the doctor with it, I did the right thing with it, but it's like everybody's looking at you crazy.*

*- Sabrina, mother of three children*

### **Preparing for Baby's Withdrawal**

Mothers tended to differ dramatically in their concerns regarding NAS symptoms. Mothers having their first baby, especially the mothers who had entered OUD through a prescription, tended to be very worried about what NAS symptoms their baby might have.

***I feel like it was kind of up in the air. When I was at the (methadone) clinic and I would ask them about it, I almost feel like they made it seem so bad, you know? Then when I finally went to Dr. Turner, she just kind of reassured me, like, “Yes. Things could possibly get this bad, but, you know, you’re doing everything you need to do.”***

*- Brittany, mother of four month old baby*

***No matter how prepared you are, I mean even just thinking about it now makes me want to cry...I am carrying this child inside of my body and if something is wrong with him, it’s my fault - that’s how I’m going to feel, whether it’s rational or not. Even if it can’t be attributed to Suboxone, you’re going to.***

*- Amy, mother of 12 month old*

Two of the mothers who had a long history of substance use disorder and OUD through all of their pregnancies (one was pregnant with her fourth baby, one had recently given birth to her sixth baby) downplayed the NAS symptoms.

***My sister has had four babies and she used during all her pregnancies. All her babies were fine. I think they try to scare you and tell you how bad it might be (baby’s withdrawal).***

*- Valerie, pregnant with second baby*

Because there was so much focus on the mother’s OUD, it seemed as though nicotine use was not focused on as much during pregnancy. Eight of the mothers were smoking while pregnant, but all said they did not realize their baby would also have withdrawal symptoms from nicotine after birth, in addition to opioids. This led to additional guilt.

***I had never heard that babies withdrawal from nicotine. There was nothing I could have done about him withdrawing from MAT, but if I had known he would have had withdrawal symptoms from nicotine, I could have quit smoking.***

*- Brittany, mother of four month old*

## **DCS Involvement**

For mothers who had entered into OUD through a prescription and had no history of substance abuse, the thought of potentially having a DCS visit after birth was extremely upsetting and embarrassing. For others who had past experience with DCS, and most had children removed from their care either in the past or presently had children who were in foster care, the upcoming DCS visit after birth was met with fear and anger.

***If you test positive, they call DCS, and you know you’re gonna test positive because you’ve been honest about it. You’ve told them you’re gonna test positive. And so I think we could do a much better job of preparing women for the fact that your baby’s umbilical cord will be tested, they will call DCS, what that visit is gonna look like, you may have an open case for six months. And getting them ready for that so that when it happens, you’re not just having given birth, worrying.***

*- Sabrina, mother of three children*



*They knew that they were taking my baby and everything like that, but they didn't tell me. I didn't know. I didn't know until 15 minutes before I was getting ready to leave. I was getting ready to walk out the door with my kids and DCS came in to take my baby from me...I was just like, that's the worst thing for anybody to ever go through in their life. I wouldn't wish it on anybody. Even now that's what I keep stressing on. I'm like, I wish I knew for sure yes or no, so that way I'm still gonna be devastated and it's still gonna kill me, but I feel like I can prepare for it better if I know. You know what I mean?*

*- Meghan, pregnant with fourth baby, older three children are in foster care*

## More Trained Physicians

The physician the mother saw for prenatal care made a significant difference in women beginning or staying on MAT during pregnancy and how prepared women felt in dealing with their baby's withdrawal symptoms after birth. The majority of the women were patients of Sarah Turner, MD. Women who had been through a previous pregnancy with another physician saw a significant difference in seeing a physician with specialized training in OUD.

*I started with Subutex (obtained illicitly) and then I finally got in with my doctor and she actually, Dr. Turner, she works with that (MAT). I love her. She is awesome. The best doctor I've ever had. I was honest with her and I said I had been on the Subutex for about a week and....I didn't know if that was good for the baby or not.*

*- Meghan, pregnant with fourth baby. She dealt with SUD or OUD during all of her pregnancies.*

**It would be so great if there was a universal curriculum that started when a woman with substance use disorder got pregnant. To have a timeline all the way from pregnancy, to birth, to all of the check-ups and included in there is, have you had your DCS evaluation? To provide that and to be able to paint a portrait of a beautiful picture of a healthy pregnancy and a healthy baby. And could we have this education developed, like, yesterday?**

**Dr. Tony GiaQuinta, Fort Wayne pediatrician, President of the Indiana Association of Pediatricians, 2018.2019**

The one mother who was not seeing Dr. Turner expressed her frustration in being honest with her physician about her OUD but not being given resources. In her third trimester this mother went to the emergency room after not having the money to purchase illicit opioids, starting to withdrawal, and having a seizure. She started MAT near the end of her pregnancy. Three weeks after her baby was born she had relapsed and was not able to care for her baby, who was removed from her care.

*I told the doctor I was using and he said to stop and it isn't good for me and the baby. But he didn't give us any resources or tell me what to do or help me. I wanted to try to go into a three day treatment but every place I called either wouldn't take my insurance (Medicaid) or wouldn't take a pregnant woman. They just kept telling me not to do drugs, but when I tried to stop I realized I couldn't. I didn't know I was addicted until I tried to stop. So tell me, how was I supposed to stop?*

*- Amber, age 19. Mother of newborn baby.*

More than one mother reported going to a physician during their recent pregnancy, or during a past pregnancy, who told them to immediately stop using opioids, not having the training to understand what the protocol should be with a pregnant woman with OUD.

*And there was even a point early in my pregnancy before I got to Sarah (Turner) where I was, I had just moved here and I was trying to find a doctor, and I went into withdrawal, and someone told me to go into the ER in Angola. So I went in, and the ER doctor did the whole, “You’re a junkie” thing. He didn’t know what Suboxone was, but he was like, “You don’t need it...” I was like, “Look, I’m telling you there’s a risk that I could miscarry,” and he was like, “No.” He just treated me like I was just some junkie and he wouldn’t help me. I was told that it was illegal for them to refuse you at that point in the ER, but he straight up was like, “Yeah, you don’t need it, you’re not going to miscarry, blah, blah, blah.”*

*- Amy, mother of 12 month-old who has been on MAT for ten years, talking about moving from out of state and having her Suboxone prescription lapse*

## Education

In the interviews, the most repeated need mothers stated was more education about NAS, what to expect in the hospital with withdrawal, and what to expect if there was involvement with DCS. Most had not heard of the Finnegan Scale used to track their baby’s withdrawal symptoms, when symptoms were likely to start, and how they could help their baby.

Nine of the mothers had stable cell phone numbers (the same number for at least six months). One mother had experienced homelessness during the early stages of her pregnancy and was living with her father and sharing his cell phone. All ten women desired education to be delivered through their phone on an app (rather than on a website) and to be in short video format. Most would also like to have additional print information that they could access if desired, as long as the main information was in the video.

*I think I have like three of those (pregnancy) apps. I remember looking at all of them just to compare, just because I know that no one was in my situation (on MAT) ... When Dr. Turner was telling me about this project, it was just like, “This is gonna help people in my situation so much.”*

*- Sabrina, mother of three, youngest is seven weeks old.*

*That would be awesome. That would be ... Yeah, that would be life-changing for me just ... seriously, that is a very good idea.*

*- Tanya, mother of six, speaking in relation to the app and to a safe place for women to share their experiences.*

Having a trusted source of information was important, many mothers expressed frustration with going online to search for NAS symptoms and not knowing what information was valid.

*I would have wanted to know what she is going to go through (NAS), what I should look for and what could happen. I feel like I was told nothing. I feel like I was judged and they thought I was going to be a bad mom anyway so why tell me anything.*

*- Amber, age 19. Mother of newborn baby.*

*And until you see it first hand (baby’s withdrawal), you just don’t believe it. But it is for real. If I had a chance to do this again, it would be completely different...So I feel like moms should be walked through, step by step, of what is really about to happen with the baby, but not in a way where it’s like, it scares them, but just in a way so that they know this is what is going to happen, and just so they’re just prepared for all of it, like what you’re doing.*

*- Sabrina, mother of 7 week old baby. Baby is not meeting developmental milestones.*

Having a safe environment to share their concerns and experiences was also important. Many mothers had shared their OUD status on chat rooms and had been harshly judged.

***And it's not worth it. It's not worth getting attacked, especially when you're pregnant and they are stressing you out making you think that you're hurting your baby, making you think that you're a horrible mother. Just because you made a comment.***

*- Valerie, pregnant with second baby, first baby was placed for adoption.*

## Developing an Educational Intervention

Women with opioid use disorder are an extremely vulnerable population. Nearly all have a co-diagnosis of depression/anxiety – all ten of the women we interviewed had this co-diagnosis. In addition, most feel extreme guilt and shame about taking opioids while they were pregnant, even if it was through a medication-assisted treatment (MAT) program. Many had an unpleasant experience while their baby was hospitalized and all could recount statements made by medical personnel that they felt were intended to be shaming. Many are hiding their OUD from everyone but their partner and one or two others and do not have a strong support system.

A new Indiana law requires a health care provider to: (1) use a validated and evidence based verbal screening tool to assess a substance use disorder in pregnancy for all pregnant women who are seen by the health care provider; and (2) if the health care provider identifies a pregnant woman who has a substance use disorder and is not currently receiving treatment, provide treatment or refer the patient. The results disclosed by a woman or the results of testing cannot automatically be shared with law enforcement or DCS.

When a woman with OUD begins MAT during pregnancy, her baby is automatically tested for opioids at birth and will test positive. Although this positive test does not necessitate a report to DCS, if other substances are identified in the cord blood test, a report may be made. Other observations during the hospital stay may necessitate a report. The goal of DCS caseworkers is to ensure the safety of the home environment and to keep families unified, if possible. However, women are often anxious that their baby will be removed from their home, even if they are in recovery. The relapse rate in the first six months after birth is extremely high, in part due to the high rate of postpartum depression these women suffer. If women are covered by Medicaid insurance during their pregnancy, it is likely they will lose this coverage shortly after birth. If a woman has no other insurance coverage, the cost of MAT is also often a barrier to staying in a treatment plan.

In designing an educational intervention, we need to understand most of our citizens do not read at a high level. Overall, 29% of our population is reading at a 5th-6th grade reading level, and another 14% are functionally illiterate. Lower-income individuals tend to have lower reading levels (Kutner, et al., 2006). Any intervention working with the Medicaid population should not develop materials written above a 6th grade reading level; a good portion of this population will not be able to read any materials. Currently, the majority of information being given to women who have babies with NAS is in written format and most is written substantially above a 6th grade reading level.

New mothers are primarily from our younger population, who prefer to access information online, especially in video format. All ten of the mothers interviewed said they would prefer education to be in a short video format. None preferred written materials only, although most were fine with written materials as a follow-up to the videos.

The most effective way to connect and educate women and professionals would be an app that can be accessed through a cell phone. This would allow for presentation of education in video and written format and allow women and professionals to track progress, appointments kept, etc.

## During our interviews, what we heard from mothers with opioid use disorder is that they need:

- More education, beginning in pregnancy.
- Accurate information. They are overwhelmed by the amount of information online and have trouble knowing what information is correct.
- A chat room where they can converse with women sharing the same experience. They are afraid to talk on most chat sites because they feel they will be judged for being on MAT while pregnant.
- More details on the withdrawal symptoms their baby may experience after birth, and what they can do to help reduce those symptoms.
- More information on developmental milestones and how to help their baby reach those milestones.
- Understanding how the Department of Child Services (DCS) may be involved after their baby is born and what to expect if a report is made.
- A way to connect with other mothers sharing the same experience.
- Judgement-free and supportive education.
- Education specifically about the impact of MAT during pregnancy.
- Education to be online so they can access it through their phone/laptop.
- The format of the education to be short videos with follow-up reading.
- Education about the impact of tobacco/vaping use while pregnant and the withdrawal symptoms their baby may have from nicotine exposure in utero.

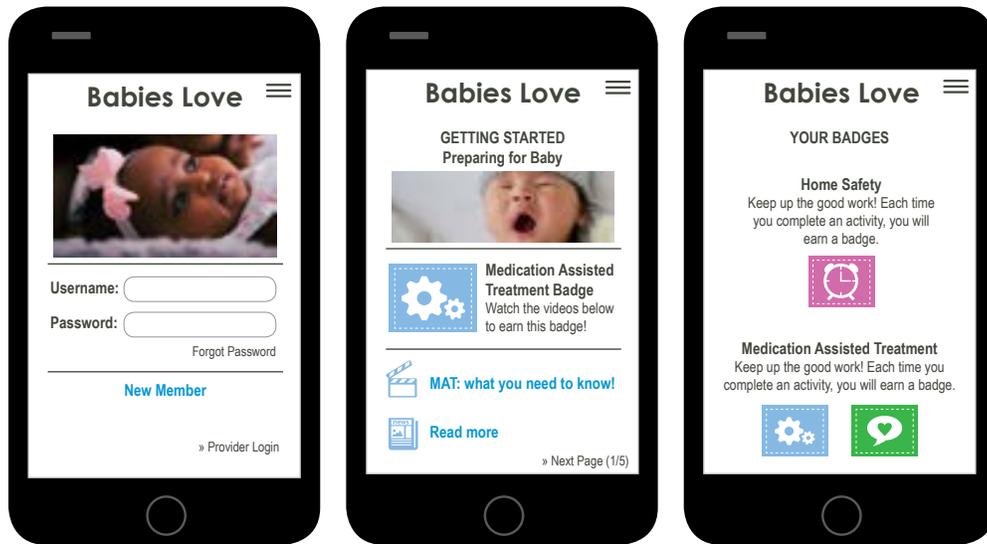
Pregnancy and parenting apps have become very popular with new parents because they reach parents in the educational style they prefer. However, many apps designed for educational purposes still tend to rely on written information, which is not the style preferred by younger and lower literacy parents. In addition, most apps are not designed to track educational content and achievement, nor are they designed for the professionals working with at-risk parents to be able to track parents' achievements on the app.

A potential pregnancy app for pregnant women with OUD could be designed for use as part of a home visiting or case worker curriculum. Women not enrolled in a home visiting program could also have the option of accessing the app directly. The education could be structured with topics for every month of pregnancy which will make it ideal for home visitors, community health workers, or social workers to use with their clients.

### Use of App in Practice

While the app could be open to anyone who would like to view the content, it would be designed to be used by community health workers, home visitors and other professionals who work with at-risk parents. Professionals using the app would have clients create an app login, which would also allow them to choose which professionals could view their progress. Professionals would be able to have their agency listed, and when approved by the parent, would be able to view the parent's progress.

The app would potentially look like this:



Home visitors would review app content either with their clients, or the clients could view the content on their own between home visits. Each component would give parents the ability to earn a badge and track their progress. After watching each short video there would be three questions to determine knowledge gained. When the questions are answered correctly a component of a badge would be earned. When all videos have had their questions answered correctly the entire badge would be earned. For instance, in the section regarding NAS there may be several short videos covering what symptoms a baby may have, how the hospital will measure symptoms, what parents can do to reduce symptoms, etc. The goal would be to present content in small, easy to understand segments. Written materials would be available as supplemental reading for parents with higher literacy levels, but only the videos would need to be watched to gain all of the required content.

Home visitors would be given training, an interactive facilitator's guide, and corollary parent materials which would guide them in the ideal way to present the content and how to use motivational interviewing questions to determine a mother's attitude toward the content. Content would be delivered during pregnancy, but also after baby arrives to ensure mothers are aware of the developmental milestones their baby should be reaching and to deliver content related to Safe, Stable, Nurturing Families.

## Interviews with Professionals

Seventeen professionals who work in some aspect with mothers with OUD were interviewed. They were asked what education they felt mothers need and what features they would want mobile education to have. Many did not work with substance use disorders on a regular basis and felt very uncertain about correct recommendations and where to refer women. A frequent comment was the need for training for professionals and providing them with resources for the women they work with.

### What we heard from professionals in relation to what education they would want women to receive:

- Many understand how judged and stigmatized women in this situation feel and encourage education that gives them a way to connect to each other.
- They want women to understand the importance of being honest with her medical provider about her opioid or substance use during pregnancy.

- They want women to have more information about the importance of the medical home and making sure their baby/toddler is on track developmentally.
- Because most women with OUD have a co-diagnosis of depression or anxiety, they want a strong mental health component.
- Education on recovery issues and the importance of continuing their treatment, especially after birth.

**The proposed education would have a professional component, which would allow professionals who have been granted access to view a woman's educational progress through badges earned, appointments kept, etc. In relation to the professional aspect of the app what we heard was desired is:**

- Education on OUD and MAT for those professionals who do not work in recovery.
- A way to see what appointments a woman has kept.
- To be able to suggest educational topics for mothers/fathers to watch/read.
- A component that talks about the Department of Child Services (DCS) and what their role is.
- Education to begin in pregnancy and be in a format that could be used by home visiting organizations and other groups who work with mothers.
- An app with a page that shows a woman's progress in education and other areas.
- The Family Court, which hears cases determining removal of children from the home, wants mothers to understand how to prepare for court hearings and what steps they should take to prepare for a hearing.

***Right now our community health workers are going out and talking about safe sleep and shaken baby syndrome and they could easily do this as well (education about NAS). But I don't have anything to give them. I have nothing.***

*- Erin Norton, RN, BSN, MBA, Director Community Outreach, Women's & Children's Service Line, Parkview Regional Medical Center*

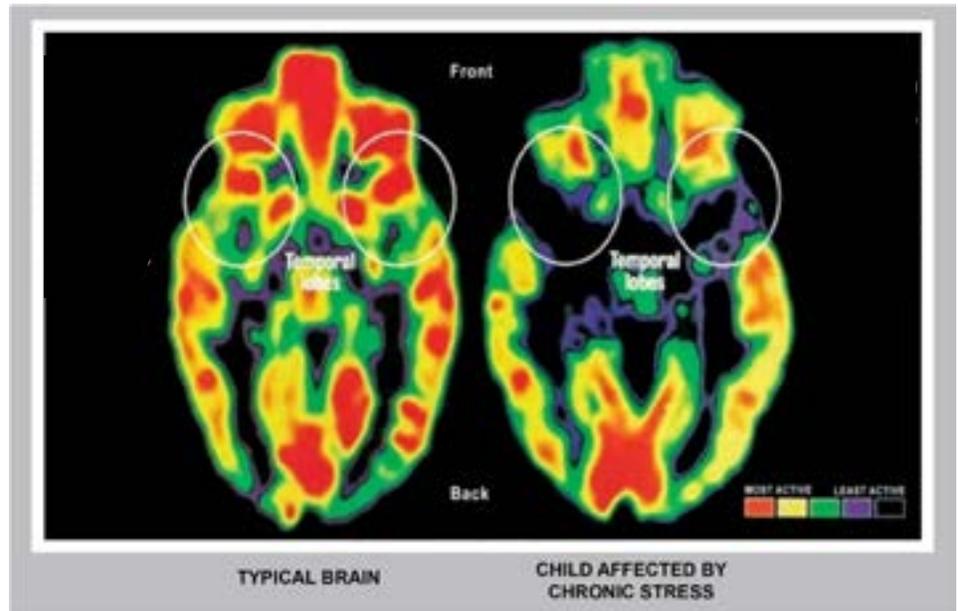
## **The Safe Stable Nurturing Families Framework**

The app design and the education delivered in the app would use the Safe Stable Nurturing Families (SSNF) Framework. This framework is promoted by the CDC as being shown to prevent the detrimental intellectual and health effects of childhood trauma (CDC, 2014). This is especially important as women fighting addiction often live in a stressful home situation, which raises their child's incidence of chronic stress. New research shows children living in stressful situations will also be predisposed to substance use. As many as 50% of people with childhood trauma will develop an addiction. This has been tied to stress changing the structure of the immune cells and inflammatory response, which leads to increased drug-seeking behavior (Iacono et al., 2018). If we want to prevent substance use in the next generation, reducing stress levels in the home is critical.

Studies have shown women who misuse opioids typically live in poverty and often suffer from depression. Many are misusing other substances and alcohol. A history of substance abuse is common with their family, friends and romantic partners and one-third report experiencing domestic violence. While many want to enter treatment, they also fear they will lose custody of their children if they come forward and acknowledge their substance use disorder (Powis et al., 2000).

The chronic stress that results from this lifestyle can change the physical structure of their baby's growing brain, resulting in developmental delays and behavior issues. Much of the brain changes due to chronic stress are attributed to the increased levels of cortisol these children's brains are exposed to (Deater-Deckard et al., 2010; Finer & Zolna, 2014). Brain changes can begin in utero; this highlights the importance of intervention during pregnancy and infancy.

The brain scan on the right shows a healthy brain on the left and the brain of a child who is living in a stressful situation on the right and how brain activity is reduced. Common stressful situations include poverty, drug/alcohol use in the home, domestic violence, parent incarcerated, living in an unsafe home, etc. Since research has shown women with OUD live with many of these situations, their children are at high risk of brain impact unless specific measures are taken to create a stable home with nurturing relationships. It is important to teach mothers and their partners the concepts which have been shown to offset chronic stress: safety, stability, and nurturing. We can then measure if these skills are helping them to bond with their baby and for their baby to thrive.



Not only are infants at risk, but often mothers have had cognitive impact from their own exposure to chronic stress. In the interviews, nearly all of the women said they had lost friends or family members to overdoses and were dealing with grief and childhood trauma. Family practice physician Dr. Sarah Turner, who works with a number of pregnant women with OUD, indicated that nearly all of her patients have experienced trauma in their past. Most also developed substance abuse disorder in their teens, which impacts their neurocognitive development. She states that this reduces their ability to learn new information, develop coping skills, and make mature decisions. "Just because a woman in my care is 35 years old, it doesn't mean she has the mentality and the maturity of a 35 year old."

By giving women the tools they need to form a secure attachment with their baby and provide a safe, stable, nurturing environment, this project hopes to reduce the impact on their child's brain from chronic stress, allowing their children to reach their full potential.

**Opening in 1981, McMillen Health is one of the few independent non-profit health education centers in the US. Our mission is to provide vital, effective, preventive health education that promotes physical, emotional, and social well-being. We offer programs in a variety of formats: at our facility in Fort Wayne; via outreach where our educators travel to a school or community site; through online education; and nationwide and internationally via live interactive distance learning.**

**McMillen Health offers more than 90 programs for youth and adults and provided direct education to nearly 90,000 in 2018.2019. In addition to our direct programming, we develop curriculum and educational resources, primarily for high-risk audiences. Recent projects include our own Brush oral health curriculum which serves over 1.6 million pregnant women and children nationwide through Head Start and WIC; developing asthma curriculum for parents of preschoolers for Johns Hopkins University; and developing secondhand smoke curriculum for the Indiana State Department of Health.**

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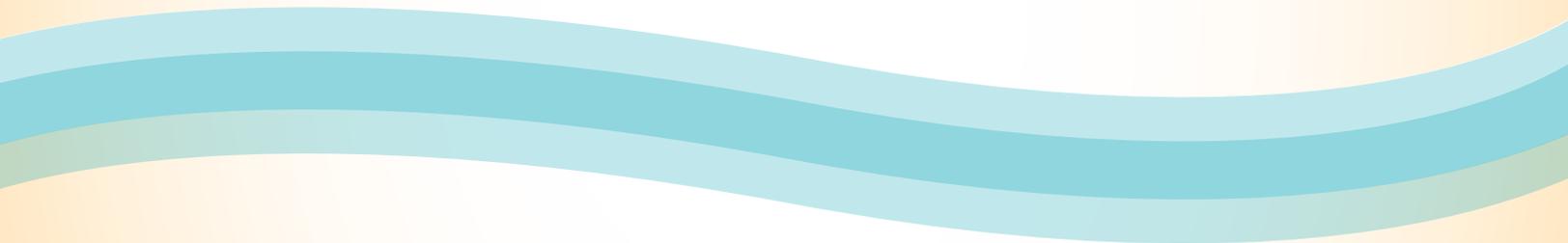
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