



**ARIZONA SUBSTANCE ABUSE TASK FORCE
Neonatal Abstinence Syndrome Work Group**

**June 9, 2016
1:00 p.m.
Governor's Executive Tower
Suite – 230
1700 West Washington Street
Phoenix, Arizona 85007**

A general meeting of the Neonatal Abstinence Syndrome Work Group was convened on June 9, 2016 at 1700 Washington Street, Suite 230 Phoenix Arizona, 85007, notice having been duly given.

Members Present (10)	
Debbie Moak , Governor's Office of Youth, Faith and Family	
Beckett, Cindy , Flagstaff Medical Center	
Kate Brophy-McGee , Legislator	
Jennifer Carussetta , Health System Alliance of Arizona	
Elaine Ellis , Phoenix Children's Hospital	
Deb Gullett , Arizona Association of Health Plans	
Thelma Ross , Community Member	
Rick Sloan , Compassionate Care Centers	
Glenn Waterkotte , Retired Neonatal Abstinence Syndrome Doctor	
Michael White , Community Medical Services	
Staff/Guests Present (7)	Members Absent (0)
Sharon Flanagan-Hyde , Flanagan-Hyde Associates	
Theresa Gonzales , AHCCCS	
Tara Sundem , Member of the Public	
Ingrid Gaving , Member of the Public	
Kelly Woody , Member of the Public	
Kathy Baris , Member of the Public	
Carol Thagnese , Member of the Public	

A. Call to Order

Co-Chair **Debbie Moak** called the meeting to order at approximately 1:00 p.m.

B. Welcome and Introductions

Sharon Flanagan-Hyde asked the work group members to introduce themselves. She reminded the group of their norms which included:

- Members are to speak candidly
- One person should speak at a time
- Be respectful
- Self-monitor to ensure there are no tangents
- Work toward consensus

C. Approval of the Meeting Minutes

The meeting minutes for the May 12, 2016 meeting were approved without modification/change.

D. Volunteer to Report at the Task Force Meeting

Sharon asked for a volunteer to report on the Neonatal Abstinence Syndrome (NAS) Work Group's updates at the Arizona Substance Abuse Task Force meeting that is scheduled to occur on June 22, 2016. No members volunteered to report at this time. Sharon will ask again at a later time.

E. Presentation on NAS Facility for New Borns

Guest Presenter, **Tara Sundem and Kelly Woody** presented on NAS Facility for Newborns.

- **Tara and Kelly** are Neonatal Nurse Practitioners in Arizona with a combined experience of over 50 years in the NICU. They have a vision for creating residential treatment facilities for babies born with NAS.
- They have never before seen the current number of babies born with NAS.
- Both **Tara and Kelly** have suffered personal losses due to substance abuse.
- Their mission is "We will provide a therapeutic and inviting environment of short-term medical care to infants suffering from Neonatal Abstinence Syndrome and their families. We seek to offer non-judgmental support, education, and counseling to families in a cost effective manner."
- **Tara and Kelly** were looking for similar facilities across the country and came across Lily's Place in West Virginia and contacted them.
- They believe that babies with NAS shouldn't remain in hospital NICUs, which are crowded and loud and nurses aren't always trained on how to properly treat them. The overstimulation of the NICU works against weaning NAS babies from opioids and leads to longer lengths of stay.
- There is no need to reinvent the wheel as Lily's Place is a successfully running a non-profit NAS residential facility.
- Lily's Place in West Virginia has created a book about how to run a neonatal withdrawal center. Due to the high degree of interest, Lily's Place hired a consulting firm to help others create these centers across the country, and will be putting out more information such as webinars and checklists shortly.
- Lily's Place currently has 12 beds and can expand up to 24 beds.
- **Tara and Kelly** expect that they will need a dedicated staff consisting of an Executive Director, Director of Nursing, designated Social Worker, Secretary, 24-7 Security Guards, RNs, CNAs/CMAs, and volunteers.

- They want to hire the right people who are cut out to do this and are calm and patient.
- They expressed that building an NAS residential facility was the right thing to do and would address the growing number of NAS babies locally and nationally.
- NICU environment is too stimulating for babies born with NAS.
- Babies need to have people willing to nurture them and not judge the mothers.
- Parents are not always accountable, mothers of some babies born with NAS have not gotten help for themselves. Mothers need to get help while they are with us.
- Special training will be provided for all volunteers on the needs of the babies. It is important to get to the baby before they start crying and workers need training to do it, not all NICU nurses have that training.
- There would be a cost savings to taxpayers. Otherwise healthy babies who need to withdraw, don't need to be in NICU to withdraw. The facility would not take in babies with special needs beyond withdrawing.
- Lily's Place costs up to 75% less than the hospital.
- **Tara** and **Kelly** would like to encompass the whole family and would like to partner with our non-profits and DCS.
- The facility could be a Safe Haven for mothers to drop off their child if they are unable to provide care.
- **Tara** and **Kelly** expressed the need to start this facility now.
- Lily's Place was started with donated real estate. A new residential facility could be started in vacant buildings owned by the state.
- They analyzed ZIP codes and found the highest rate of NAS is in East Mesa and Apache Junction. They originally wanted to be in that ZIP code, but want to be anywhere that is accessible to the parents and where services can be provided to the whole family. (**Glenn Watercotte** said that an obstetrician in Mesa specializes in women with substance addiction; that likely explains the ZIP code data, which indicates the location of delivery, not the mother's home address. The obstetrician on staff is an expert in handling pregnancy and opioid dependency, and provides a unique viewpoint and specialty.)
- The NAS Residential Facility needs to be safe environment with a security system and cameras. There is especially a concern because the facility will dispense narcotics, even though the amounts are small.
- **Tara** and **Kelly** met with Vitalyst (formerly St. Luke's Health Initiatives) to discuss Vitalyst serving as a fiscal agent, which eliminates the need to immediately get 501(c)3 status. They would be under Vitalyst's 501(c)3 status, and Vitalyst would provide grant writing, payroll, and other business services.
- In West Virginia, legislative action was needed to create a licensing category and requirements for NAS Residential Facilities. In Arizona, the facility may be able to fall under an existing licensing category.
- There is widespread support and many others have responded to creating this facility. **Tara** and **Kelly** want to continue to network and connect with resources, and provide education to mothers about NAS.

- **Tara and Kelly's** vision is to identify pregnant moms and get them into early treatment, possibly partnering with first responders, who could provide contact information to pregnant women using substances.
- They would like to explain NAS to mothers.
- They would like to work with DCS as a newborn foster option.
- They plan on becoming a diaper bank. Diapers aren't covered by WIC, children cannot go to daycare without diapers and many families are choosing between diapers and food.
- They will inspire others to open NAS residential treatment facilities across the country.
- They will develop outreach education programs.
- The goal is for total family recovery and keeping babies with their mothers.

Discussion

- When will the facility be opened?
 - The facility does not have a location and not sure when they will be open.
- This facility would be an opportunity to create model for best practices.
- Engaging the full family could be a difficult task and a lot to take on.
- **Tara and Kelly** hope to partner with other organizations so that their facility can focus on taking care of the babies while other groups can take care of the mothers. They want to have an agreement that moms will seek treatment for themselves and spend time with their baby at the residential facility.
- Will the mother stay with child?
 - The mothers will not be living there. The Lily's Place model does not allow parents to stay overnight, except for nesting right before discharge.
- Center for Hope was brought up as an example of providing pregnant mothers with treatment and can provide housing for the mother and baby once discharged from the hospital.
- It is best for mother and baby to stay together.
- Feeding mothers and babies is difficult and a strain on resources. Current system is similar to what the hospital has in place.
- Some mothers can read the baby's withdrawal cues better than nurses.
- Dartmouth study and European study show that it is best practice for mothers to stay with the baby.
- Ideas are cheap and implementation is important.
- Have you talked to anyone or are you aware that DCS has a Healthy Families program?
 - **Kelly and Tara** responded yes.
- This program can be expanded up to 5 years and can help mothers get clean.
- There are requirements for facilities where methadone is distributed even in small doses. Is there a plan for pharmaceutical support?
 - There is a plan for meeting these requirements and it is discussed in the book. Lily's Place outsources medication to a pharmacy for compounding which provides services for free.
- In Wales there is a robust study, which follows children 9 years out and found an increase in neglect and abuse for children whose parents abuse substances. This study shows the

need to educate mothers and takes neonatal abstinence syndrome to the pediatrician level of responsibility.

- A good NAS program will have long-term accountability or efforts to assist mothers built in, including parent education.
- How do you get babies to the facility from hospital?
 - When a baby is born they can show symptoms from 3-5 days. When they get to a certain score they go to the NICU for morphine treatment, when scores get less than 8 and stable, which takes about a week, then they don't need an NICU, they would then be transferred to the NAS Residential Facility which would use therapeutic techniques and could treat the baby faster than at hospital, because the environment is quieter and designed to service the needs of NAS babies.
- When you are moving baby from hospital to the facility is that by non-emergency transport?
 - We can't allow parents to take them, it would be by non-emergency ambulance and Medicaid would pay for it.
 - This transportation model is already used for step-down units.
- Why wouldn't the parent drive during the transition?
 - It would be a huge flight risk, DCS comes in right after a positive drug test. The parents believe they are an appropriate parent and don't want to risk losing the child. Some parents already try to walk out of the hospital with the baby.
 - Doctor has to write order to transfer baby and is medically responsible for who they discharge the baby to.
- 70% of babies suffering NAS are AHCCCS babies. There is a financial incentive for the payer to move forward with an NAS Residential Facility.
- AHCCCS spends \$60 million on these babies.
- AHCCCS has an application to the federal government for Delivery System Reform Incentive Payment (DSRIP). This fits into the DSRIP application regarding how to improve care for DCS children. Some of this money could be earmarked for treatment of these children and switching from the NICU to a NAS Residential Facility would be an example of switching delivery models.
- It is important to have mom and babies together. Also, early intervention and prevention is lacking.
- The only way to redirect dollars to the front end is to do something like this and first focus on the baby. If we can help the babies in a more cost-effective way, more money can be put towards the front end.
- Looking at best practices: Hospitals could have rooming in as a best practice and for the moms that are missing in action, the residential facility could be the second level.
- Rooming in would also be less costly than the NICU and preserves the family.
- There is a fussy baby model regarding babies that are neurologically wired to be fussy. This could provide a plan on how to do intervention with mothers and babies and could be a best practice.
- Many addicted mothers are not capable and most don't get their baby, not sure how to change it, can't make an addict accept help.

- First Things First shows that the first 3 years of a child's life make the largest difference. Transition of specially challenged babies is within the goals of First Things First and could be another resource.
- How long do you expect these babies on average to stay?
 - 6-8 weeks, based on their experience.
- In the NICU, average length of stay was 34 days and they believe they could cut down on that time. The length of stay could be attributable to the hospital environment.
- When you are looking at becoming a Safe Haven you may want to look into statute, you may not fall into the provider categories.
- There are great organizations in the community to partner with such as Changing Lives Center.
- It is important to provide services, including housing, to pregnant women and many pregnant women are not taught how to care for the babies.
- Would the grading scale change with in-room nesting?
 - Banner uses a modified scoring scale. There is a lot of nurse dependence on the current scale. Banner's new scoring system is not working and they will be changing it.
 - Nurses don't just go by the scoring system but use professional judgment while seeing the baby.
- This does not apply to marijuana?
 - No, it only applies to opiates and benzodiazepines. Babies do not have physical withdrawal from marijuana. Nicotine and anti-depressants do cause withdrawal, but there is no treatment available.

F. Discussion: Presentations- What Stood Out

No discussion occurred on this topic.

G. Review of Integrated Notes

- Sober Living Home comment: Stated they aren't regulated or licensed, which changed a few years ago, and thinks they should be regulated. Through interacting with drug courts, we have found that unregulated sober living homes often become drug houses.
- Consider arranging for a presentation from DHS about licensure for the whole task force.
- Comment about the format of the notes: Every topic should be sorted differently so it is not like a stew.
 - This version is just a working document and in September it will look much more like a report.
- We need more information on the courts and the process of the courts.

H. Review of Information Provided by Dr. Bartos

- **Cindy Becket** is working closely with Dr. Rene Bartos to recruit representation from all AHCCCS providers to put together tool kit to screen, identify, and treat women using substances.
- The group is meeting: The Arizona Statewide Task Force on Preventing Prenatal Exposure to Alcohol and Other Drugs, created under Governor Napolitano.
- That group is revising identification of best practices among AHCCCS providers and developing a protocol for use with all mothers.
- How can Mercy Care's efforts be expanded to other health plans or other provider leadership?
 - The biggest challenge will be reaching out to all the providers.
- Would the Arizona Perinatal Trust be a mechanism?
 - Yes, the Perinatal Trust certifies hospitals by level of care provided and would be willing to take appropriate standards and fold them into certification process.
 - More than 98% of NAS births are in Perinatal Trust certified hospitals.
- **Glenn** provided a personal perspective of this problem: He remembers what the country looked like when littering was considered acceptable, it was everywhere and routine, this country got behind changing the perception of littering to where now someone might pull over and pick up litter they see. Cultural change of this magnitude is necessary to address NAS.
- This cultural change is happening nationwide and this is not out of our control.

I. What Additional Information Do You Need?

- Most opioid dependent mothers don't start when they become pregnant. Would like to explore opportunities around the controlled substance monitoring program passed by the legislature.
- **Glenn** would like to see a system similar to what is established for syphilis where a positive test puts the mother immediately into treatment, and expanded services are provided for baby and family.
- Physicians may not know to go deeper in counseling and providing information to the patient if the patient doesn't volunteer information regarding opioid abuse.
- Birth is traumatic event and the mother may know that she wants to get help at that point, but if she isn't in services already, there is a high likelihood for relapse.
- If mothers are abusing drugs they are probably not getting prenatal care.
- Some providers don't ask questions regarding substance abuse in a way that will obtain an honest answer because they don't know where to send the woman if she is abusing drugs.
- The Coleman Institute has successfully detoxed pregnant women.

J. Call to the Public

- **Kathy Davis** has 32 years of experience primarily focused on neonatal care and has seen firsthand babies who suffer from NAS. Some of them scream out in discomfort from the symptoms and rub their skin raw. She has seen babies discharged with no outfit or car seat and nurses that give higher scores than are necessary instead of comforting the baby.

Not all babies have mothers who want help. The NAS Residential Facility would provide for the child during the two-month period they are passively dependent.

- **Dr. Peter Coleman would** like to help with a pilot program to detox pregnant women who are dependent on opioids. Though he has never focused on NAS, he has successfully detoxed women using Vivitrol implants and they have all delivered healthy babies without NAS. Detox may not be for all women but for the right person it could prevent NAS altogether. The women can also stay on Vivitrol after the birth while they are learning to take care of the baby.

K. Adjourn

Debbie adjourned the meeting at approximately 2:55 p.m.

Dated May 20, 2016
Arizona Neonatal Abstinence Syndrome Work Group
Respectfully Submitted By:
Christopher Vinyard
Arizona Health Care Cost Containment System