

Meeting Minutes
Substance Exposed Newborn Taskforce
May 4, 2016
1:00pm – 2:35pm
Pioneer Room

Attendees: Claire Ness, Duane Stanley, Maggie Anderson, Senator Nichole Poolman, Representative Alan Fehr, Kathleen Murray, Tina Bay, Pam Sagness, Dr. Karen Brown, Christie Spooner (phone), Sandy Tibke, Scot Davis – did not vote, Dr. Kathy Anderson – did not vote.

Reviewed Minutes for both December and March

For both December and March meeting minutes, cite the following statutes:

Endangerment of Child or Vulnerable Adult 19-03.1-22.2

Ingesting a Controlled Substance 19-03.1-22.3

Add page numbers to the minutes.

Add 27-20-13 and 27-20-06 statute citations to the bottom of page 6 to help give people the opportunity to view the various ways removal can take place.

Add statute citation 50-21.1-03 (mandated reporter information) to page 4 of the December minutes. This will provide additional clarification for why you “may report, may refer”. Specific sections include, 50-25.1-16 (1), 50-25.1-16 (4), 50-25.1-18 (1), and 50-25.1-18 (3). Also, add statute citation 19-03.1-22.3 regarding ingestion.

Kathleen made a motion to approve the minutes with the changes that were discussed. Senator Poolman seconded the motion. Roll call taken with all present agreeing to approve the minutes with the changes that were discussed.

Thank you to Pam, Marlys, Maggie and others at DHS. Pam put together the visual. Four goals and recommendations for each time along the timeline.

A two page visual document was created that summarized the Task Force recommendations and the report to Legislative Management. The document is user-friendly and highlights recommendations for legislators, the public, administrative agencies, etc. The visual document was created with the intent to capture people’s attention and result in policy and/or legislative changes to start addressing the issues surrounding substance exposed newborns.

In the goals section – change neonatal substance use/abuse. Even usage can cause this not just abuse. These were created directly from the Senate bill that created the Taskforce. This will be changed to be visually represented.

University of North Dakota – Claire just obtained information confirming our findings about the findings and costs of NAS. Claire will add this information to the background section. University of North Dakota also stated they would be interested in partnering on research issues. Add to background section.

Comments on The North Dakota Task Force on Substance Exposed Newborns recommendations:

Bullet 1 – Currently states, “Addiction and drug abuse during pregnancy should be treated as a health issue rather than criminalized.”

Request to change the wording so there are no implications regarding the Task Force stating we don’t have to make any changes to the current laws. The Task Force agrees current laws should be changed and Health is the priority. At some end of the spectrum, if the user/abuser continues to use and doesn’t change to prioritize their children, criminal charges are needed.

Change Bullet 1 – Addiction and drug abuse during pregnancy should be treated as a health issue since research shows universal criminalization has been ineffective.

Bullet 8 – Currently states, “Medical professionals should follow the current laws for testing, referring, follow-up and reporting pregnant women who are abusing alcohol or using controlled substances and for reporting substance exposed newborns.” There was a discussion regarding concerns that some of the laws should be revised and protocols should be changed and/or identified although there wasn’t a consensus on the specific changes necessary at this time. Agreed to repeat what the draft says regarding the need to review the criminal laws and follow-up and add language regarding protocols (CPS, Medical, Etc.) that are easier to understand. This could be done in statutory notes.

Bullet 2 – NAS is not defined although it is defined in the draft.

Bullet 4 – Currently states, “The state should work to ensure health care providers are informed of – and encouraged to refer patients to – addiction treatment resources as necessary. One way to do so is to ensure a list of those resources is made available to health care providers. Another is to bring medical and behavioral health providers together to share information and strategies for coordinating treatment of patients.”

Concerns that referring patients is not the “best way” rather the “best way” would be to have the services integrated with the health care at the clinic. Concerns were expressed surrounding referrals due to the decrease of follow-through when people are referred to a separate agency. They are more likely to follow-through if they can obtain/participate in services at one location.

The optimal outcome would be having the services brought to the patient at the health care facility where they are seeing their health care professional.

As a Task Force we don’t have the expertise to make a detailed recommendation of how the care and coordination should occur. The point of the bullet is we should as state agencies work to inform the licensed behavioral health practitioners of the available resources. Coordination of care is much more of a traditional way of thinking of things. Integration of care is a whole different level.

Change the last sentence in bullet 4 to read: Another is to bring medical and behavioral health providers together to share information and strategies for integrating and coordinating treatment of patients.

Bullet 5 and Bullet 9 – Concerns expressed regarding the Task Force addressing both prevention and early intervention. With early intervention, someone has already been identified as at risk while no one has been identified as at risk for prevention. Have we covered prevention? Bullet 3 addresses

developing educational materials and an awareness campaign to educate women and their families. Bullet 2 addresses gathering the data to make an informed prevention campaign.

Bullet 3 identifies the State as the one who should develop materials. Concerns expressed regarding the assumption that these materials would get into the hands of health care professionals, etc. Bullet 3 is meant to address education on a global universal level, with prevention and awareness prior to a woman becoming pregnant being the focus. The target audience would be woman of child-bearing age. If we are talking about the health care professionals having the information to distribute then we are at the intervention level rather than prevention. It is important to target the audience as much as possible while also recognizing culture.

Without identifying specific appropriations, the Task Force doesn't have enough information to identify who should be responsible for developing educational materials and how various entities will be trained. Concerns were expressed that if it is an action item without an actor, it won't get implemented. Due to funding/appropriations, specific role identification is limited although the Task Force was able to identify some specific initiatives such as the SEOW which is out of the Department of Human Services. From prevention and marketing perspective, there needs to be a collaborative effort to ensure the information provided will resonate with the target audience. Some of the educational materials identified have already been created - they will only need adjusted to be North Dakota specific. If materials are available, various avenues can be utilized for training including the UND Children and Family Services Training Center, established committees, and stakeholder groups.

Bullet 11, 12, and 13 – In regards to these bullets, in saying this group needs education, does this go back to bullet 3 and the state developing the education? Bullet 3 focuses on the general pre-pregnancy population and is true global prevention and promotion. Bullets 11, 12, 13 are focused on communication and education. Creating awareness for who is providing care afterwards. That is a whole different audience then the primary audience and we need to be really clear about the audience.

Various programs are already providing training and awareness. We need to meet the target group but also provide those who are meeting with the target group (physicians, social workers, law enforcement, etc.) with the necessary information.

North Dakota has a Global Clearinghouse that provides substance abuse and behavioral health resources to anyone across the state at no cost – shipped directly to them.

Bullet 14 – This bullet raises attention regarding having an Affirmative Defense available and the possibility of it being something that can be looked at further by another group. There was enough interest to pursue but as a Task Force, there was not a consensus to make specific recommendations regarding Affirmative Defense and whether or not this would be added into statute.

The behavioral health community made comments referencing having Affirmative Defense in statute. If it is in statute and if it appears to be something that the mother is compelled to do, it may be a compulsory thing to do to stay out of jail and less effective. Various pros and cons discussed.

Title 50 references a referral not having to be made if a person voluntarily goes to treatment. An affirmative defense would give us some avenues to say here is a statutory provision to provide more uniformity because right now, it is very inconsistent across the state in terms of how law

enforcement, social workers, prosecutors, etc. handle these cases. If we have it listed, it can be a future discussion.

Affirmative Defense was a strong enough talking point in the Task Force that it merits future discussion.

In regards to health care professions, there are no protocols. There needs to be a definite path with uniform requirements that need to be met. There was agreement that they don't need to criminalize mothers yet but there should be requirements to achieve.

Bullets 5 and 6 address protocols. Concerns expressed in regards to expanding these bullets for developing protocols for how to handle this situation.

Bullet 6 – There are efforts currently being made towards implementing universal screenings although this is only being done at one hospital and that hospital doesn't want to appear to be profiling. More data needs to be collected and having a uniform protocol for screening will only support the data. Pediatricians are looking for direction regarding how to screen, where to go with a screen, etc.

Bullet 14 – Should there be a policy or rule/law for aggregate data. There needs to be a conversation regarding mandated to, by who. Specifically, resources and authority need to be addressed.

Bullet 16 – States, “Residential pediatric care centers that provide wrap-around services for children with NAS and their families should be established.” Can you have a residential care center with one child, one family. You need numbers.

This stemmed from a discussion about Lily's Place that has garnered a lot of news in West Virginia. It is basically about getting more data about the incidents of how many babies are affected with NAS and how many babies in our community are affected with this problem. This data will inform our decision regarding how many centers are wanted/needed. This stems from the discussion of needing to have in-home visits. This is the alternative that you have a place for moms to go. If you have a mom who is overwhelmed and takes the high needs baby home, who does the mother go to. If you don't have someone coming into the home regularly, which can be quite expensive, here is an alternative. This is a safe welcoming place for the mom to go that she can bring the baby and seek counseling and get assistance and support. If you don't build the trust and rapport the mom might not seek services.

The Federal Cradle Act under consideration in the House of Representatives and the Senate (and in some states) pertains to providing Medicaid funding for these types of centers. The Legislature determines if they want to fund this either through Medicaid or other sources. The Task Force cannot get too specific with their recommendation other than identifying this is a good idea. But we can't say how many or where without the data and we can't talk about the funding or who is going to do it because that is out of our hands.

Home visits.....

If the numbers justify the funding, residential facilities may be considered depending on the funding. Even without the robust data, the Legislature could make a decision to have small residential facilities (example 8 cribs) with the understanding that this is a significant issue and this may be a

way to provide support/services. Additionally, current facilities could be encouraged to expand their services and identify themselves as a facility that accepts both mothers and babies.

Working with current substance abuse providers to educate and focus on best practices. There are opportunities to offer additional supports by answering questions such as: how do I go to treatment, what do I do with my child, do I have to move, can I take my baby, etc. A residential pediatric care center would give mothers the opportunity where they could work on the skills that intensive in-home and parent aide try to teach them but how do they get over their own substance abuse issues and work on the various skills.

Bullet 17 – Information should be made available. Who would do this? Is this the state? Ideally although unsure of who would do this. While the thought is that maybe DPI and DHS may be able to provide information, concerns were expressed that if the Task Force identifies specific agencies and their responsibilities, you run the risk of having a state agency saying they don't have an FTE or they don't have the funding to create educational materials.

If we add to this bullet, the committee is suggesting the previous specific recommendations so the information is available. Bullet 17 is a summary saying all of the previous points need to be developed so we can work together. There are lots of materials available and they can be attached to the report if the Task Force would like. Additionally, the materials can be adjusted so they are more appropriate for our desired audience.

Bullet 15 – When you talk about funding programs for home visitation programs, concerns were expressed that funding could be impacted by specifically identifying one home visitation program.

Bullet 11 – It wouldn't be only county social services that provide direct support to parents. Add directive service providers.....county social services and direct service providers.

Public Comments:

Roxanne Romanich - Essentially IDA is the basis for Part C Early Intervention and within that law is the requirement to make a referral to Part C within 7 days if a person is concerned about a child's development. Substance Exposed Infants have automatic eligibility that is available right away but funds are limited with a federal grant and additional state and Medicaid funds. Once they are eligible for that service, they have to put a plan in place which would include a direct provision of services. ND does this by having providers who hire PTs, OTs, Speech Early Childhood Special Educators, Social Workers, Etc. If a child goes into foster care and they are referred to Early Intervention, they can provide support around the needs of the infant around things like self-regulation, calming, feeding and all of the things you are concerned about with an infant who is struggling as well as communicating with the physicians. Early Intervention is also an entity that can be utilized for training for local county social workers as their staff have the expertise in what infants need.

It would be beneficial to develop protocols to ensure all hospitals across ND are making referrals when appropriate. Some hospital staff feel confident their hospital is making referrals but Having a protocol to refer. The system may break due to but that will show the need for an increase in

Some Task Force members would like the Task Force to do something more formal as medical professionals are seeking guidance and the thought is this would help with data collection. With the Task Force having only four meetings, this limits what can be done in the Task Force but the work doesn't have to be finished. Hopefully something that will come out of the Task Force

recommendations is outreach back to the communities of medical providers and their work with the NDAP and AAP and trying to get some of these protocols in place. It may be helpful to take the recommendations and say the Task Force strongly encourages universal screenings for data collection and avoiding the appearance of profiling. Hopefully these recommendations can lend support to these efforts and if there is more work that can be done, that is something that needs to be advocated by members of the Task Force. Within the balance of what the Task Force has been tasked with, the Task Force doesn't have the mandate to get into the detail. There are a lot of things that the Task Force has been identified as having to happen as this is an underserved issue in North Dakota.

Task Force members were encouraged to work collaboratively to contact the University of North Dakota to identify specifics regarding costs, what is needed, who else could be needed, etc. to then move forward through the legislative process and bring forward an appropriations bill.

List the actual statutes as a footnote to page 12 of the draft so they can be referenced.

Neglect of a Child 14-09-22.1

Endangerment of Child or Vulnerable Adult 19-03.1-22.2

Abuse of Child 14-09-22

Ingesting a Controlled Substance 19-03.1-22.3

A suggestion was made to utilize the ND Indian Affairs Commission office moving forward as this office this work encompasses Legislative, Executive, and Judicial opinions. This office is an entity that is already in place and has stable government to government relationships with the tribes, federal agencies, etc.

The information from today will be added into the report and necessary changes made to the visual document. This report will be presented to the Judiciary Committee in June.

Concerns were expressed that pediatricians from Standing Rock are not receiving discharge summaries and mothers are not seeking prenatal care, so they don't know the infants exist. This is a challenge as a lot of this is the responsibility of the patient. Also concerns noted that more infants are testing positive for Hepatitis C. Also, some mothers working with chronic pain management are not given pregnancy tests and pregnant women are not forthcoming when they are pregnant. A suggestion was made to develop protocol for those utilizing chronic pain management services.

**North Dakota Task Force on Substance
Exposed Newborns (2015-2016)**

Report to Legislative Management

**FINAL REPORT
June 17, 2016**

I. Introduction

Senate Bill 2367 in the sixty-fourth Legislative Assembly created a task force on substance exposed newborns “for the purpose of researching the impact of substance abuse and neonatal withdrawal syndrome, evaluating effective strategies for treatment and prevention and providing policy recommendations.” The task force was directed to provide a report on its findings and recommendations to legislative management before July 1, 2016. The members of the task force hereby submit this report in fulfillment of their obligation under the senate bill.

The task force on substance exposed newborns was comprised of representatives of state agencies, the legislature, medical providers, nonprofit entities focused on children’s health and wellbeing, Indian tribes, law enforcement, and the foster care community.¹ The membership represented diverse viewpoints and experiences. This diversity was essential to developing a fuller understanding of the myriad of issues involved with substance exposed newborns. The task force noted, however, that one key group of specialists was not represented. Due to the importance of prevention and early intervention, the task force believed it would have benefitted from having a member who is an obstetrician. Nonetheless, the task force brought together many stakeholders to address this important issue.

Senate Bill 2367 required the task force to meet quarterly for one year, beginning in the fall of 2015. It also set forth four goals for the task force to address during that one-year period. They were:

1. Collect and organize data concerning the nature and extent of neonatal withdrawal syndrome from substance abuse in this state;
2. Collect and organize data concerning the costs associated with treating expectant mothers and newborns suffering from withdrawal [from] substance abuse;
3. Identify available federal, state and local programs that provide services to mothers who abuse drugs or alcohol and to newborns who have neonatal withdrawal syndrome and evaluate those programs and services to determine if gaps in programs or ineffective policies exist; and
4. Evaluate methods to increase public awareness of the dangers associated with substance abuse, particularly to women, expectant mothers and newborns.

The task force has gathered data and information on these four issues and discussed them at length during its meetings. The task force recognizes the budget limitations state government faces and developed its recommendations based on best practices with the budget reality in mind.

¹ S.B. 2367 dictated how the members of the task force were selected and is attached as Exhibit A. A full list of the members is attached to this report as Exhibit B.

II. Data concerning the nature, extent and cost of neonatal withdrawal syndrome in North Dakota

Neonatal withdrawal syndrome (also known as neonatal abstinence syndrome or NAS) is the severe group of symptoms experienced by newborns whose mothers used alcohol or other addictive drugs during pregnancy. When a pregnant mother uses these substances, the substances pass through the placenta to the baby, and the baby becomes addicted to them. When the baby is born, the supply of the alcohol or drugs ends, and the baby suffers withdrawal. The acute symptoms of NAS in a newborn baby include: excessive or high-pitched crying, vomiting, diarrhea, feeding difficulty, low birth weight, fevers, seizures, respiratory distress, sensitivity to light and noise, irritability, sleep difficulty, sweating, tremors and more. The chronic symptoms may include lifelong physical and developmental impairments requiring specialized services from health care providers, social services and educators. The exact symptoms a child experiences depend on multiple factors, including the drug at issue, its dose and frequency, the child's and mother's metabolic and excretory rates and the timing of the last intrauterine exposure to the drug.

The task force identified a lack of data regarding the incidence of NAS in North Dakota. Although several states have examined this issue, it remains difficult to quantify and qualify. Many children who were exposed to alcohol or drugs in utero are simply not identified prenatally or at birth.² This stems, in part, from the fact that hospitals generally do not screen all newborns for NAS. Different hospitals in the state have different policies on when and how to screen for NAS. Additionally, medical records and insurance records may not specify that a child has NAS, so reviews of these records are an unreliable method for determining the incidence of NAS. For example, medical records may identify only certain symptoms of the syndrome rather than the syndrome itself.³ Further complicating the collection of data is the fact that the signs and symptoms of NAS may not manifest until after discharge from the hospital. Some symptoms of NAS resulting from opioids may be delayed until five or more days after birth, for example.⁴ For these and other reasons, the incidence data presented in this report is, at best, an estimate that almost certainly errs on the side of underreporting.

² U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, "Substance-Exposed Infants: State Responses to the Program, p. 18 (2009).

³ Hospitals and insurers use codes from the International Statistical Classification of Diseases and Related Health Problems (ICD) to identify patients' diagnoses. The ICD is on its 10th revision, and the codes are now known as ICD-10 codes. The ICD-10 code for "neonatal withdrawal symptoms from maternal use of drugs of addiction" is P96.1. Providers may use a myriad of other codes for a newborn with NAS, however. For example, the records for a child with NAS may include Code P22.8 "other respiratory distress of newborn," Code P92.9 "feeding problem of newborn (unspecified)," or any of the several codes for low birth weight or other symptoms of NAS.

⁴ Committee on Drugs and Committee on the Fetus and Newborn, *Neonatal Drug Withdrawal*, *Pediatrics* (Feb. 2012) <http://pediatrics.aappublications.org/content/129/2/e540#T2>.

A. National Data on Incidence and Cost of NAS:

According to the National Institutes of Health (NIH), 21,732 babies were born with neonatal abstinence syndrome (NAS) in the United States in 2012.⁵ Not only is this a large number in itself, especially considering it most likely underreports the issue, it also represents a 500 percent increase since 2000.⁶ NIH found that babies with NAS are more likely to have respiratory problems and low birth weights, contributing to an average neonatal hospital stay of 16.9 days for them.⁷ As a comparison, babies without NAS have an average neonatal stay of only 2.1 days.⁸ Similarly, other researchers found the number of neonatal intensive care unit stays due to NAS increased 700 percent between 2004 and 2013 and the average length of those stays increased from 13 days to 19 days during that time period.⁹ Researchers and public health agencies agree the incidence of NAS is growing significantly.

Many researchers and commenters have attributed the increase in NAS, at least in part, to the rapid growth in the national opioid abuse epidemic.¹⁰ The epidemic includes abuse of both prescribed and illegal opioids such as heroin. Opioids are not the only drugs that cause NAS, however. Cocaine, barbituates, alcohol and methamphetamines are some of the many other contributors to NAS.

According to the NIH, the lengthy neonatal hospital stays for babies with NAS in 2012 alone cost approximately \$1.5 billion, with more than 80 percent of those costs (more than \$1.2 billion) borne by Medicaid, which is funded jointly by federal and state governments.¹¹ Similarly, the National Association of State and Territorial Health Officials estimates that Medicaid covers 78 percent of babies born with NAS.¹² Beyond the neonatal period, Medicaid incurs extra health care costs for each baby born with NAS throughout his or her childhood. Tennessee's Medicaid program, for example, estimates it expends \$40,000 just for the first year of life, on average, for each baby born with NAS.¹³ This is nine times as much as the

⁵ National Institutes of Health, National Institute on Drug Abuse, *Dramatic Increases in Maternal Opioid Use and Neonatal Abstinence Syndrome*, www.drugabuse.gov/related-topics/trends-statistics/infographics/dramatic-increases-in-maternal-opioid-use-neonatal-abstinence-syndrome (Feb. 23, 2016). See also USA Today, *Born into Suffering: More Babies Arrive Dependent on Drugs* (July 8, 2015) (citing an article in the *Journal of Perinatology* by Vanderbilt University researchers).

⁶ *Id.*

⁷ *Id.*

⁸ *Id.*

⁹ Anand KJ, Campbell-Yeo M. Consequences of prenatal opioid use for newborns. *Acta Paediatr.* 2015 Nov. 104 (11):1066-9.

¹⁰ National Association of State and Territorial Health Officials, *Neonatal Abstinence Syndrome: How States Can Help Advance the Knowledge Base for Primary Prevention and Best Practices of Care*, p. 3 (2014).

¹¹ National Institutes of Health, National Institute on Drug Abuse, *Dramatic Increases in Maternal Opioid Use and Neonatal Abstinence Syndrome*, www.drugabuse.gov/related-topics/trends-statistics/infographics/dramatic-increases-in-maternal-opioid-use-neonatal-abstinence-syndrome (Feb. 23, 2016). Also, Testimony of Stephen W. Patrick, MD, MPH, MS, before the United State House of representatives Committee on Energy and Commerce Subcommittee on Health, Hearing on H.R. 1462 (June 25, 2015).

¹² National Association of State and Territorial Health Officials, *Neonatal Abstinence Syndrome: How States Can Help Advance the Knowledge Base for Primary Prevention and Best Practices of Care*, p. 5 (2014).

¹³ National Association of State and Territorial Health Officials, *Neonatal Abstinence Syndrome: How States Can Help Advance the Knowledge Base for Primary Prevention and Best Practices of Care*, p. 6 (2014).

state's Medicaid program expends on a child without NAS during its first year of life.¹⁴ This tremendous impact on state Medicaid budgets is one of the reasons NAS is such an urgent issue for states.

In addition to the extremely high costs of caring for a child with NAS during his or her infancy, states incur additional costs related to the child's additional needs for social services, educational interventions and health care. These needs generally stem from the child's in utero exposure to drugs and depend on many factors. Longitudinal studies have shown children exposed to drugs in utero can have lasting physical, neurodevelopmental, speech and behavioral problems including irritability, aggression, depression and others. Medicaid programs, state health and social services agencies and school systems often provide the bulk of services to address these problems.

¹⁴ Id.

B. North Dakota Data on Incidence and Cost of NAS:

Despite the difficulty of obtaining data on the incidence of substance exposed newborns, the task force was able to find the following state-specific information for North Dakota.

The North Dakota Department of Human Services provided the following data from state Medicaid claims. Approximately 120 babies born in fiscal year 2013 were diagnosed with NAS. The average cost to North Dakota Medicaid for the first year of life for a baby born with NAS is approximately \$19,300, compared to \$8,200 for a baby born without NAS. Using the difference of the average costs, children diagnosed with NAS incurred medical expenses estimated to cost North Dakota Medicaid at least \$1,332,000 in fiscal year 2013. Considering the impacts of underdiagnosing, increasing opioid addiction rates and increasing hospital costs, that figure has likely risen significantly since 2013.

Almost 6 percent of women who are admitted to treatment programs for substance abuse in North Dakota are pregnant.¹⁵

One insurer in North Dakota reviewed their claims data to help determine the incidence of NAS in North Dakota. They identified ten babies diagnosed with NAS during their neonatal period in 2014 and 2015.¹⁶ Those babies' neonatal hospital charges amounted to more than \$1,055,000. Since most babies with NAS are not diagnosed with the syndrome, these data most likely underreport the incidence and cost of NAS to insurers in our state.

At the December 17, 2015, Tribal and State Relations Committee meeting, tribal representatives noted the Three Affiliated Tribes, Spirit Lake Tribe and Turtle Mountain Tribe reported approximately 183 babies were born with NAS last year.

The North Dakota Department of Human Services found at least 67 pregnant substance abusers sought treatment at Human Service Centers in state fiscal year 2014. Pregnant women are prioritized by the centers, and all 67 women were offered services within 48 hours of contacting the centers.

Dr. Larry Burd, a longtime researcher of Fetal Alcohol Syndrome Disorder (FASD) at the University of North Dakota School of Medicine and Health Sciences, has found that approximately 80 children born in this state each year have FASD. He estimates that, "on the day before the child with FASD is born, North Dakota needs to deposit over \$540,000 in the bank to cover the lifetime cost of care [for that one child]."

¹⁵ National Center on Substance Abuse and Child Welfare: Substance Exposed Infants, Presentation at 2011 National Conference.

¹⁶ Specifically, the insurer identified ten babies whose initial newborn inpatient claims included the ICD-9 diagnosis codes 779 and 779.5.

While these data provide some insight into the incidence and cost of NAS, they are incomplete. To truly understand the incidence and cost of NAS in North Dakota, the state needs short- and long-term trend (year-over-year) data. Such data would also provide important information on whether any implemented interventions are effective. The first step to developing trend data is to establish a baseline. The task force recommends that individuals trained in statistical analysis and public health determine how best to establish the baseline and develop the trend data.

One group with the skills to help fill NAS data gaps is the North Dakota State Epidemiological Outcomes Workgroup (SEOW). That workgroup was initiated in 2006 by the Division of Mental Health and Substance Abuse Services in the North Dakota Department of Human Services to use relevant data to guide substance abuse prevention programming in North Dakota. It is funded with federal funds. The SEOW members also have expertise on using health care data to guide policy and program decisions relating to substance abuse. Such expertise is needed to fully quantify the incidence of neonatal withdrawal syndrome and effectively engage state residents in efforts to prevent it.

III. Discussion of Available Services and Programs and Task Force Recommendations

A major theme of the task force's discussions was that substance exposure in utero creates chronic problems for children rather than acute problems that are present only during the neonatal period. As a result, addressing the problem of substance exposed newborns really requires focus on multiple life stages of the mother and child. This report therefore includes analyses and recommendations for the following life stages: (1) pre-pregnancy, (2) prenatal period, (3) birth and neonatal period, and (4) childhood. This framework is used by other states and policymakers as well.¹⁷

In addition to the life stages, one overarching recommendation is to utilize the North Dakota Indian Affairs Commission office through established government to government committees such as: Tribal-State Court Affairs Committee, The Tribal-State Relations Committee, and the Tribal State Health and Human Services Committee. Currently, these committees all serve on-going Tribal, State, County, and Federal working relations in regards to Memorandums of Agreements/Understanding, Jurisdiction, and Sovereignty in working together towards common goals.

A. *Pre-pregnancy*

The task force members believe the best way to address newborn withdrawal syndrome is to prevent it. In order to prevent it, it is important to provide targeted education and outreach to women of childbearing age before they become pregnant. Moreover, there should be education efforts aimed at the general population so significant others, family members and friends can help reinforce them. The federal government and several other states have implemented public awareness campaigns on the dangers of substance use - usually alcohol use - during pregnancy, but data on their effectiveness are difficult to find.¹⁸ There are several confounding variables that make it difficult to isolate the impact that these campaigns have. Nonetheless, at least in Minnesota, this type of campaign appears to have at least raised awareness of the harms of substance use during pregnancy.¹⁹ The Department of Human Services' Behavioral Health Division is uniquely positioned in North Dakota to develop and implement an effective educational campaign along these lines, and the task force recommends that it do so.

In addition to education efforts, there also need to be adequate treatment options for women with addictions. The North Dakota Department of Human Services (DHS) licenses more than 50 private addiction treatment programs in the state.²⁰ These treatment programs provide multiple levels of residential and outpatient treatment. DHS also operates the state

¹⁷ National Association of State and Territorial Health Officials, *Neonatal Abstinence Syndrome: How States Can Help Advance the Knowledge Base for Primary Prevention and Best Practices of Care*, p. 3 (2014).

¹⁸ U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, *"Substance-Exposed Infants: State Responses to the Program*, pp. 22-25, 60 (2009).

¹⁹ U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, *"Substance-Exposed Infants: State Responses to the Program*, p. 60 (2009).

²⁰ North Dakota Department of Human Services, *Licensed Addiction Treatment Programs in North Dakota* <http://www.nd.gov/dhs/info/pubs/docs/mhsa/nd-licensed-addiction-treatment-programs.pdf>

hospital in Jamestown, which provides inpatient addiction treatment and eight Regional Human Services Centers that provide outpatient addiction treatment. The Regional Human Services Centers are located in Williston (Region 1), Minot (Region 2), Devils Lake (Region 3), Grand Forks (Region 4), Fargo (Region 5), Jamestown (Region 6), Bismarck (Region 7) and Dickinson (Region 8). Additionally, Regions 2, 3, 4, 5, 6, and 8 have outreach offices in smaller communities within their geographic areas.

Some patients face financial barriers to treatment, although there are many options available to make treatment more affordable. Medicaid generally covers addiction treatment, so Medicaid patients can obtain treatment if they find a provider who accepts Medicaid payment.²¹ For non-Medicaid patients, the Regional Human Services Centers use a sliding scale based on a patient's income to determine charges for addiction treatment. Under the federal Mental Health Parity and Addiction Equity Act, private insurers must provide coverage for mental health care, including addiction treatment, to the same extent they cover physical health care. The specific requirements of the law are very detailed, however, and patients and providers in North Dakota have reported difficulty in obtaining insurance coverage for some types of addiction treatment services. With the passage of Senate Bill 2048 during the 64th Legislative Session, \$375,000 will be available to fund a voucher system to pay for substance use disorder treatment services in North Dakota.

While some rural patients may lack access to local addiction treatment and some non-Medicaid patients may lack insurance coverage (e.g., because they opt out of employer plans and the Affordable Care Act health insurance exchange), funding for addiction treatment in North Dakota is generally good. However, the services provided are not necessarily best practice or effective. For example, medication assisted treatment options are limited and only available in limited areas of the state. In addition, funding for and access to recovery support services is limited. Individuals who access acute treatment services are often without adequate aftercare services or supports. In addition, whether patients know where to find treatment is another question. The task force heard lots of anecdotal evidence that patients and providers often lack knowledge about available treatment resources. The task force recommends that health care providers be informed of - and encouraged to refer to - the department's list of addiction treatment resources so they can refer patients as necessary. Additionally, to the extent there is funding available, the task force recommends that the Department of Human Services look for opportunities to bring health care providers and addiction treatment providers together to share information and strategies for integrating and coordinating treatment of patients.

²¹ Medicaid coverage includes addiction treatment services; however, Medicaid cannot cover services for individuals age 21-64 in an Institution for Mental Disease, in residential settings except in limited circumstances under Medicaid expansion), and services for individuals who are incarcerated.

B. Pregnancy

During pregnancy, women in North Dakota have largely the same access to education and treatment options as they did before pregnancy. The department's Regional Human Services Centers prioritize pregnant women with a substance use disorder, so they can receive treatment quickly. As noted above, the Department of Human Services reports that pregnant substance abusers receive care within 48 hours of first contact with the service centers. The task force discussed the difficulty in identifying pregnant substance abusers and getting them to seek help, however.

To help identify pregnant substance abusers, the American Congress of Obstetricians and Gynecologists (ACOG) recommends universal substance use screening in early pregnancy.²² The Association of State and Territorial Health Officials (ASTHO) suggests states can encourage this universal screening by ensuring Medicaid reimburses providers for early pregnancy visits that include screening and by helping establish screening during early pregnancy as the expected standard of care for pregnant women.²³ North Dakota's Medicaid program allows payment for substance abuse screening in conjunction with a diagnosis of pregnancy. Also, the task force recommends that universal substance use screening in early pregnancy be established as the standard of care in our state. Establishing a standard of care will require cooperation among state agencies and medical providers.

Substance abuse screening cannot occur in early pregnancy if the patient does not see an obstetrician until the end of her first trimester (as is typical), however. The task force believes medical office receptionists can play a critical role in identifying which newly-pregnant patients may be using drugs and scheduling early appointments for them. The task force recommends obstetrician offices train receptionists to ask questions designed to solicit information to identify possible substance abusers for this purpose.

If a pregnant women screens positive for substance use, her health care provider will need to know what services are available. Timely referrals to treatment services are critical to prevent and minimize the severity of NAS. Moreover, health care providers may need to provide care coordination to pregnant substance abusers (i.e. reminders and phone calls to ensure they attend medical and addiction treatment appointments). This is yet another reason why cooperation between obstetricians and addiction treatment providers is necessary. The task force recommends providers are educated on the standard of care, including medications or methadone where medically warranted, for pregnant women addicted to drugs or alcohol so appropriate interventions can be taken to minimize the incidence and severity of NAS.

Compelling addiction treatment is very difficult. In order to require a pregnant woman to obtain addiction treatment against her will, she would have to be involuntarily committed to a behavioral health services provider such as the State Hospital in Jamestown. The task force does not believe this approach would be productive as a general rule. Rather, it would likely lead to mistrust of health care providers and avoidance of prenatal care, both of which would have negative impacts on babies.

²² Association of State and Territorial Health Officials, *Neonatal Abstinence Syndrome: How States Can Help Advance the Knowledge Base for Primary Prevention and Best Practices of Care*, p. 2 (2014).

²³ *Id.*

A small handful of states have attempted to criminalize substance abuse during pregnancy. Based on data and experience, the task force strongly recommends against this approach. Early identification and intervention are critical elements in the prevention of NAS, and criminalization of drug abuse during pregnancy strongly discourages pregnant women from seeking addiction treatment and prenatal care. Without any prenatal care, a pregnant mother with an addiction is unlikely to abstain from drugs during pregnancy. As a result, criminalization appears to adversely affect babies born to addicted mothers without reducing the incidence of NAS.

C. Birth and Neonatal Period

The task force recognizes that, as a state, we need to fill data gaps and identify newborns with NAS in a timely manner to ensure they receive the help they need. As a result, the task force recommends that obstetricians, neonatal specialists, pediatricians and family care practitioners implement universal screening of newborns and children for NAS. There are multiple validated screening tools already available. One of the most commonly used is the Finnegan Neonatal Abstinence Scoring System. The task force recommends that the Department of Health work with providers to establish universal screening of neonates using a validated screening tool as a standard of care in North Dakota. Additionally, the task force recommends that payers cover the cost of administering the screening tool to newborns.

Under state law, if a physician believes, based on a medical assessment of a mother of newborn, that the mother used controlled substances for a nonmedical purpose during pregnancy, the physician must perform a toxicology test on the newborn.²⁴ If the test comes back positive or if other medical evidence of prenatal exposure to a controlled substance exists, the physician must report the results to the Department of Human Services (via the county social service office) as neglect.²⁵ Similarly, physicians, nurses, dentists, optometrists, dental hygienists, medical examiners, coroners, any other medical and mental health professionals, religious practitioners of healing arts, teachers, administrators, school counselors, addiction counselors, social workers, child care workers, foster parents, law enforcement officers, juvenile court personnel, probation officers, division of juvenile services employees, and members of the clergy who have knowledge of or reasonable cause to suspect child abuse or neglect must report that information to DHS if they obtained that information in their official capacities.²⁶ Moreover, any person may report child abuse or neglect if he or she has reasonable cause to suspect it exists.

After receiving the report, the social service office will assess the situation and make a decision about which services are necessary for the protection and treatment of the child. If the social service office finds that services are required for a newborn who has been reported as neglected, the office must also refer the child for an Early Intervention Services (EIS) evaluation. EIS are multi-disciplinary services intended to help at-risk children from birth to age five meet development milestones. They are authorized under the federal Individuals with Disabilities Education Act and are free to recipients. They are also voluntary. The state cannot require a parent to utilize EIS currently.

If child abuse²⁷ or neglect²⁸ occurs, as defined in state law, criminal charges may be brought against the perpetrator.^{29 30} The task force members discussed - but did not reach consensus on - creating an affirmative defense in law to charges of child abuse or neglect

²⁴ N.D.C.C. 50-25.1-17(2). Toxicology testing – Requirements.

²⁵ N.D.C.C. 50-25.1-17(2). Toxicology testing – Requirements.

²⁶ N.D.C.C. 50-25.1-03. Persons required and permitted to report – To whom reported. Note that clergy members do not have to report if they obtain the information in their capacity as spiritual advisors.

²⁷ N.D.C.C. 14-09-22 Abuse of child - Penalty

²⁸ N.D.C.C. 14-09-22.1 Neglect of child - Penalty

²⁹ N.D.C.C. 19-03.1-22.2 Endangerment of child or vulnerable adult.

³⁰ N.D.C.C. 19-03.1-22.3 Ingesting a controlled substance – Venue for violation – Penalty.

stemming from drug use by a parent. The affirmative defense would be available if the parent agreed to periodic drug testing and home visits. Pros and cons of this approach were addressed, and no data on the advisability and effectiveness of this approach were identified by the task force.

Newborns with NAS often have symptoms, such as feeding difficulty, agitation or fussiness, after they are discharged from the hospital. Parents, foster parents and other caregivers often have little information about NAS or what to expect with these newborns. One member of the task force - a longtime foster parent who has cared for newborns with NAS - reported that he did not receive any information or instructions from social services or hospital personnel about the special needs of the NAS newborns. He also reported that three other foster families who cared for newborns with NAS also received no information on NAS or how to respond to abnormal behaviors. The task force recommends that DHS work with county social services, physicians, addiction professionals, nurses, parent education programs and others to develop informational resources for foster families that open their homes to infants with NAS. The resources should provide education on NAS, its symptoms, how to manage the symptoms, when to seek help and whom to contact for help. Ideally, a state or county agency could offer a voluntary training presentation on NAS for foster parents who would like additional information on the condition.²⁷

While foster parents may have the patience and ability to get assistance from social services or health care providers when caring for a newborn with NAS, many addicted mothers may not. One such mother in North Dakota came forward in the media last year to share her experience of accidentally smothering her baby. Caring for a fussy, poorly feeding, sick baby stresses the already-stretched coping mechanisms of addicted mothers. The task force recommends that these mothers receive the same educational resources and voluntary training provided to foster parents before being discharged from the hospital after delivery.

Additionally, the task force recommends that the state provide funding for programs to help ensure the safety of NAS infants after they return home. Prevent Child Abuse North Dakota (PCAND) operates a program called North Dakota Maternal, Infant and Early Childhood Home Visiting (ND MIECHV), funded through a federal grant, which provides parent support and education during home visits. Home visitors spend time with parents, children and family members so they can provide information about child development, help families get connected with medical providers and other services, help reduce stressors for families and generally provide support so children and parents stay safe and healthy. Resources for the program are currently limited, but the program has been effective. One key to its success is the fact that the home visitors have spent significant time in their target communities so they have built trusting relationships and earned reputations for being helpful among families that need their help. This foundation has been critical for ensuring parents and family members engage with the home visitors and accept their advice. In addition to the ND MIECHV program, North Dakota also has additional programs offering some level of

²⁷ The Tennessee Department of Children's Services created this type of training presentation, *Challenges of Foster Parents who Care for Infants with Neonatal Abstinence Syndrome*, available here: <http://www.nationalperinatal.org/Resources/conference%20handouts/FriPlen%20Helton,%20Heather%20-%20Challenges%20of%20Foster%20Parents.pdf>.

home visitation services. Home visiting programs offer a variety of family-focused services to pregnant mothers and families with infants and young children to help build strong children and families. The degree of services varies by agency, including eligibility criteria. A listing of available providers, public and private, can be found here: <http://www.ndkids.org/home-visiting-directory.html>

The task force recommends North Dakota expand on this type of program to ensure trained workers are able to prevent abuse and neglect of children born to addicted mothers.

Other nonprofits have developed different programs designed to meet the same goals as ND MIECHV. In West Virginia, for example, a nonprofit called Lily's Place offers wrap-around care and support to babies with NAS and their families. When a mother struggling with addiction or having difficulty caring for a baby with NAS feels stressed, she can bring the baby to Lily's Place, where the baby will receive care and the mom can receive counseling and information on childcare. This spring, a bipartisan bill called the Cradle Act inspired by Lily's Place and similar services was introduced in both the House of Representatives and the Senate and was supported by the American Congress of Obstetricians and Gynecologists and the March of Dimes. The Cradle Act would direct the Centers for Medicare and Medicaid Services to establish guidelines for these "residential pediatric care centers" and ensure they are eligible for Medicaid payments. The bill is currently pending in committees. Regardless of whether it is enacted at the federal level, North Dakota can pass legislation at the state level to provide funding for places like Lily's Place.

D. Childhood

The long-term effects of drug exposure in utero vary significantly but may include learning and behavior problems. It is important for health care providers, social workers and educators to be aware of the chronic symptoms of in utero exposure to drugs and be able to identify children who may be exhibiting them. Additionally, they will need to know what resources are available to assist children with those symptoms. The task force recommends that educational materials be developed for this purpose. Additionally, social workers should be able to provide resources and information on these issues to foster parents who care for children who are suffering from the long-term effects of in utero drug exposure, and the task force recommends that education information be developed for and provided to foster parents as well.

IV. Conclusion

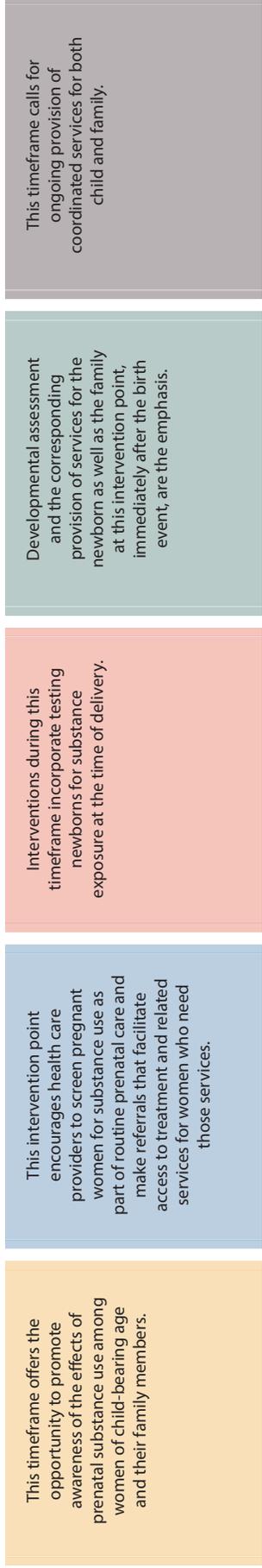
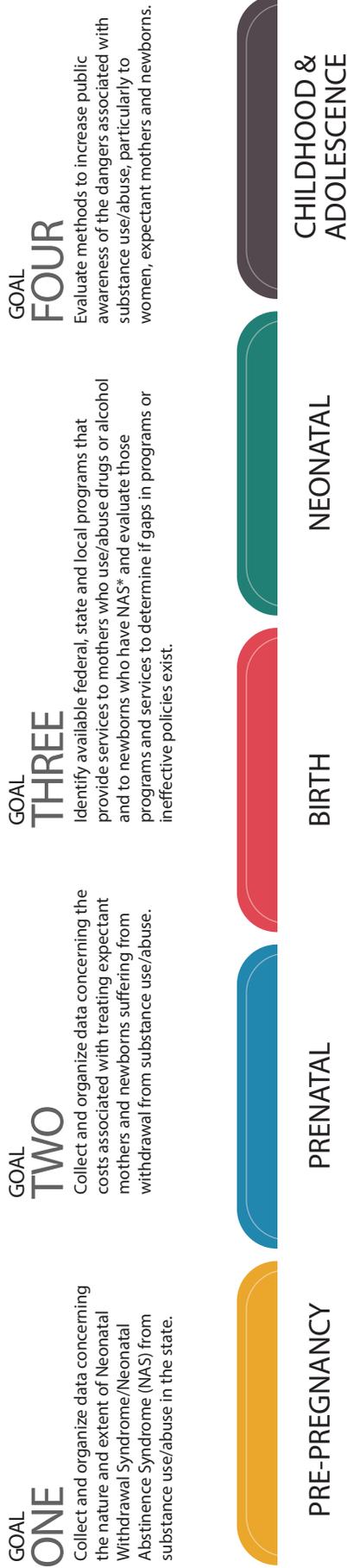
The task force has fulfilled its requirements under Senate Bill 2367. After much research and discussion, the task force identified a considerable lack of data on the incidence of NAS and the effectiveness of measures to prevent and address it. The task force believes it is critical to establish baseline incidence data and to develop trend data to determine whether and to what extent the incidence is increasing or decreasing over time. Moreover, the task force's recommendations include several methods for identifying substance abusers at risk of becoming pregnant, pregnant substance abusers, babies with NAS and children suffering long-term effects of in utero exposure to substances. The recommendations also include several methods for ensuring appropriate services are available and provided to women, babies and children identified as needing them. This will require ongoing

educational campaigns directed to health care providers, women and the general public, as well as requiring the provision of multiple services for mothers who abuse substances and babies suffering from NAS.

NORTH DAKOTA TASK FORCE ON SUBSTANCE EXPOSED NEWBORNS

Summary of Recommendations: Report to Legislative Management

The North Dakota Task Force on Substance Exposed Newborns was comprised of representatives from state agencies, the legislature, medical providers, nonprofit entities focused on children's health and wellbeing, Indian tribes, law enforcement, and the foster care community.



GENERAL CONSIDERATIONS

Addiction and drug abuse during pregnancy should be treated as a health issue since research shows universal criminalization has been ineffective.

Due to current data gaps, the North Dakota State Epidemiological Outcomes Workgroup (SEOW) should determine the best means and methods for developing short- and long-term data on the incidence and cost of Neonatal Withdrawal Syndrome/Neonatal Abstinence Syndrome (NAS).

The North Dakota Department of Health should explore mechanisms for recording data on the numbers of newborns born exposed to substances, the substances they are exposed to and the number diagnosed with NAS*.

Medical professionals should follow the current laws for testing, referring, follow-up and reporting pregnant women who are abusing alcohol or using controlled substances and for reporting substance exposed newborns.

State's attorneys and behavioral health professionals should evaluate the pros and cons of having an affirmative defense of periodic drug testing and consent to home visits in cases where criminal child abuse and neglect stems from a parent or caregiver's substance abuse.

*NAS: Neonatal Abstinence Syndrome (also known as Neonatal Withdrawal Syndrome)

	PRE-PREGNANCY	PRENATAL	BIRTH	NEONATAL	CHILDHOOD & ADOLESCENCE
POLICY					
SCREENING/INTERVENTION		<p>Medical providers of services to pregnant women should be trained about their testing, referring, follow-up and reporting responsibilities.</p> <p>Medical providers should develop consistent protocols for universal screening and testing of pregnant women.</p>	<p>Medical providers should develop consistent protocols for universal screening and testing of newborns.</p>		
SERVICES	<p>Health care providers should be informed of, and encouraged to refer patients to addiction treatment resources as necessary.</p> <p>A list of current addiction treatment resources should be made available to health care providers.</p> <p>Medical and behavioral health providers should be brought together to share information and strategies for integrating and coordinating treatment of patients.</p>	<p>Medical offices that provide care to pregnant women should develop protocols to identify patients who might be substance users/abusers and schedule appointments for them early in their pregnancies so they can receive information on the dangers of substance use/abuse as soon as possible.</p> <p>State agencies should work with medical professionals to develop standards of care for treating pregnant women who are addicted to various substances and to educate medical providers about these standards of care.</p>			<p>Funding for home visiting should be expanded and available to more families.</p> <p>Residential pediatric care centers that provide wrap-around services for children with NAs* and their families should be established and maintained.</p>

*NAS: Neonatal Abstinence Syndrome (also known as Neonatal Withdrawal Syndrome)

PRE-PREGNANCY

Develop education materials and an awareness campaign to educate women of childbearing age, as well as their significant others and families, about the dangers of substance use/abuse during pregnancy.

PRENATAL

Law enforcement officers need education regarding the reporting of substance using/abusing pregnant women to county social services.

BIRTH

NEONATAL

Hospitals and social service agencies should partner in the development of plans of safe care for each newborn born with prenatal exposure to substances, prior to discharge from the hospital following the birth. The plans should include educational materials on NAS* for parents and caregivers.

CHILDHOOD & ADOLESCENCE

Information on the possible long-term effects of NAS* should be available to educators, health care providers, social workers and foster parents so they can identify children who may have been affected by exposure to substances in utero and who need additional educational and medical care during childhood as a result.

County social services and direct service providers need training so they can better inform foster parents about care for substance exposed newborns. Social workers also need appropriate education materials and training presentations on NAS* that they can offer to foster parents.

Juvenile Court personnel need education regarding the effects of prenatal exposure to alcohol and controlled substances, the risks to newborns suffering from NAS* and the risks associated with returning a substance exposed newborn to a home with a mother who is using substances without appropriate court-ordered safety and intervention services.

*NAS: Neonatal Abstinence Syndrome (also known as Neonatal Withdrawal Syndrome)