Collaborating Across Service Systems

How to Develop a Comprehensive Data Approach for Families Affected by Prenatal Substance Exposure

A TWO-PART SERIES

BRIEF 1: State Data Collection and Reporting Approaches for Infants and Families Affected by Prenatal Substance Exposure

National Center on Substance Abuse and Child Welfare

Introduction

The National Center on Substance Abuse and Child Welfare (NCSACW) created this series for state child welfare and partner agencies (e.g., public health, maternal and child health, substance use services, mental health services) seeking to understand the scope of prenatal substance exposure (PSE) in a state or other jurisdiction. Understanding the scope requires a multiagency approach allowing for strategic planning and efficient allocation of resources to prevent and mitigate the effects on families.

Brief 1: State Data Collection and Reporting Approaches for Infants and Families Affected by Prenatal Substance Exposure

- Explores the need for a multiagency data approach to understand the scope of PSE in a state or other jurisdiction
- Explains how states collect and report data on families affected by PSE (includes responses to the Child Abuse and Prevention Treatment Act/Comprehensive Addiction and Recovery Act (CAPTA/CARA))

Brief 2: Implementation Guidance for Developing a Comprehensive Data Approach for Infants and Families Affected by Prenatal Substance Exposure

Offers three key steps to overcome common challenges in a multiagency data approach:

- Build cross-system workgroups
- Reduce barriers to cross-sector data collection and analyses
- Identify and access key data sources

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Introduction

This document describes why a comprehensive data approach—across service systems—remains critical to ensuring that systems respond to the various challenges faced by families affected by prenatal substance exposure (PSE). Also included are examples of state data collection approaches.

Background

An estimated 20% of infants in the U.S. (approximately 760,000) are born prenatally exposed to substances each year.*[1,2] Picture **25,000 classrooms** filled with children needing early intervention, special education, and other services to mitigate potential effects. PSE may result in a variety of physical, cognitive, and social-emotional consequences—each of which requires different interventions. Effects vary depending on several factors, including exposure to multiple substances, the type of substance and timing of exposure, and the birth parent's access to substance use disorder (SUD) treatment.[3,4,5]

The opioid epidemic and increasing numbers of overdose deaths serve as a "call to action" for states and other jurisdictions to ensure services remain available for families affected by PSE. The rate of opioid use disorders (OUD) among women giving birth in the U.S. *increased 131%* from 2010 through 2017 while the rate of infants with neonatal abstinence syndrome (NAS) increased 82%.[6] NAS rates vary among regions, states, and counties.[6,7] For specific information on neonatal opioid withdrawal syndrome (NOWS), please see the American Academy of Pediatrics, 2020 Clinical Report, Neonatal Withdrawal Syndrome.

A 2018 Tennessee study found elementary school children with an NAS diagnosis had an increased need for special education services—including assessment services and in-classroom interventions—compared to children without an NAS diagnosis.[8] Children with an NAS diagnosis were also more likely to meet criteria for an education disability. Specifically, 19.3% of children with an NAS diagnosis received referrals to a special education assessment while 15% met criteria for an educational disability.

Adolescents affected by PSE remain at an increased risk for mental health disorders and other concerns. Recent findings from the Adolescent Brain Cognitive Development (ABCD) study show adolescents with prenatal exposure to cannabis have an increased risk of cognitive, mental health, and other challenges—thereby increasing their risk of developing SUDs or psychiatric disorders.[9] Further, studies show

* Based on 20.6% of pregnant women report use of illicit drugs, tobacco products, and alcohol and the number of U.S. births (n=3,613,647) in 2020. Includes nine categories of illicit drug use: marijuana, cocaine, heroin, hallucinogens, inhalants, methamphetamine, misuse of prescription psychotherapeutics, opioids, and illicit drugs other than marijuana.

adolescents affected by *parental SUD* are at increased risk of developing their own SUD.[10,11] Adolescents affected by parental substance use—who have experienced out-of-home care (particularly those that *age-out* of care)—have an even higher risk of developing their own SUD as well as other concerns.[12]

Increases in drug-related hospitalizations and overdose deaths of parents or caregivers positively correlate with an increase in reports of maltreatment, substantiated reports of maltreatment, and children entering out-of-home care.[13] These data underscore a need for comprehensive services for infants, children, and adolescents with PSE—*as well as* their parents. Comprehensive services across systems include

- Family-centered SUD services and treatment (e.g., screening and assessment, medication for opioid use disorders (MOUD)) for pregnant/postpartum people and others (e.g., fathers, other caregivers)
- Residential SUD treatment for pregnant and postpartum people, fathers, and other caregivers along with their infants and children
- Early intervention for infants and children 0-3 for assessment and other services to mitigate the cognitive, physical, and other effects of PSE
- Child welfare risk and safety assessment services when necessary, as well as case management services to ensure engagement into comprehensive care
- Maternal and child health, home visiting, and peer recovery support services for care coordination
- Special education and other supports to ensure ongoing help for children, adolescents, and young adults
- Developmentally appropriate SUD prevention and treatment for children, adolescents, and young adults

For more information, see Infants with Prenatal Substance Exposure and Their Families: Five Points of Family Intervention.

A Data-Driven Approach to Developing a Comprehensive Service Array for Families Affected by PSE

Data-driven approaches remain essential to identifying: 1) the scope of service need, 2) those most affected, and 3) how to implement services where they are most needed. Each system understands the nuances of how their system functions. Collaboration across sectors allows staff to consider each system's knowledge and experiences in the context of data collection and sharing.

Data, when implemented as a tool across systems, trigger a feedback loop that allows for both the ongoing improvement of services and outcomes, as well as the continuous refinement of data collection and sharing mechanisms. This approach should also include a commitment to recognizing structural inequities and disproportionalities in service delivery and the use of data to inform policy and practice changes that reduce their effect.

A data-driven approach helps answer several important questions:

- How many infants are affected by PSE in the community, state, region?
- What are the key systems involved and how can collaborative relationships among systems be built?
- Which data are currently available and useful?
- How can these data be used to identify and reduce inequities?
- How can data be collected and shared across systems?
- How can data be used to understand the scope of unmet need?
- How can data be used to implement policy and programmatic changes?
- What structures and efforts encourage ongoing data and information sharing among systems?

State Reporting of Prenatal Substance Exposure

Plans of Safe Care (POSC), or Family Care Plans (FCP)—as a few states have named them—offer an opportunity for states, Tribal communities, and other jurisdictions to bring various service providers together in a collaborative approach. Key service providers include maternal and infant health care, child welfare, SUD treatment, mental health, early childhood development, and others.

Thirty-one states reported on the number of infants with POSC in 2021 compared to 13 in 2018.[19,20]

CAPTA (2003) required POSC for infants born and identified as being affected by illegal substance use or withdrawal symptoms.[14] It also directed health care providers involved in the delivery or care of such infants to notify child protective services (CPS). An amended CAPTA in 2010 included identification and development of POSC for infants affected by fetal alcohol spectrum disorder (FASD).[15] More recently, CARA (2016) made several amendments to CAPTA, including: 1) removal of the term "illegal" regarding infants affected by substance abuse or withdrawal symptoms, and 2) a requirement that POSC meet the needs of the infant and affected family or caregiver.[16] Other amendments cover development and implementation of POSC monitoring systems and revisions to POSC data that state child welfare systems are to report. States and other jurisdictions have implemented POSC statutes, policies, and protocols based on their unique needs.

CAPTA requires states to report specific data elements annually to the maximum extent practicable.[16] These data elements include (and herein referenced as) the "CAPTA PSE" data elements:

- Number of infants born and identified as being affected by substance abuse or withdrawal symptoms resulting from prenatal drug exposure or a fetal alcohol spectrum disorder
- Number of such infants for whom a Plan of Safe Care was developed
- Number of such infants for whom a referral was made for appropriate services, including services for the affected family or caregiver

For more information on POSC, see About CAPTA: A Legislative History, POSC Learning Modules, ACYF-CB-PI-17-02, and ACYF-CB-PI-23-01.

> An increasing number of states and other jurisdictions have adopted the term **"Family Care Plan"** as an alternative to **Plan of Safe Care.** Family Care Plan is the preferred term as it is less stigmatizing and may enhance engagement of families into services. States now implementing the term include Oklahoma and Connecticut. Certain states have adopted other terminology such as Family Wellness and Support Plans. See Model Substance Use During Pregnancy and Family Care Plans Act.

State child welfare systems report a variety of data including the CAPTA PSE data elements to Children's Bureau (CB). The data is submitted via the National Child Abuse and Neglect Data System (NCANDS) and published in the annual Child Maltreatment Report.[17] The number of states reporting on the CAPTA PSE data elements in 2021 has increased since 2018 (when reporting requirements were first required). Thirty-one states reported on the number of infants with POSC in 2021 compared to 13 in 2018.[18,19] Despite significant improvements, states report a wide range in the number of families affected by PSE. States in 2021 reported a range of 1–8,267 infants with PSE whom health care providers referred to CPS.[19]

State Data Collection Approaches to Prenatal Substance Exposure

For a more comprehensive data approach, child welfare can partner with various service systems to explore data sources in addition to the PSE data collected for—and reported under CAPTA (e.g., insurance claims data (including Medicaid) includes information on ICD diagnostic codes).† There are ICD codes specific to infants with PSE, such as those with exposure to alcohol, tobacco, opioids, or other substances; infants who exhibit symptoms of NAS; and those with FASD.

Estimates on the number of infants with PSE in a state or other jurisdiction based solely on ICD codes may fall short—potentially excluding those with exposure who either failed to receive an assessment or do not meet diagnostic criteria. Other sources of information include data regarding certificates of live birth, pregnant persons with a SUD diagnosis, or those entering SUD treatment. For detailed information on certificates of live birth and other data sources pertinent to PSE, see Brief 2: Implementation Guidance for Developing a Comprehensive Data Approach for Infants and Families Affected by Prenatal Substance Exposure. As previously noted, CAPTA requires states to report on the PSE data elements to the maximum extent practicable.

Some states have implemented PSE data collection systems in addition to (or outside of) NCANDS reporting:

CONNECTICUT

Connecticut birth hospitals enter information (e.g., potential risks) on infants with PSE into an online portal. Based on the provided information, the portal determines one of two different pathways:

- A child maltreatment report should go to the Connecticut Department of Children and Families (DCF). In this pathway, the portal system first directs the user to complete a demographic page before submitting the report. DCF develops the POSC; data from the child maltreatment report and POSC are available in the DCF child welfare data system.
- A notification, as mandated by CAPTA, should go to the Connecticut DCF. In this pathway, the birth hospital develops a POSC with the family. Staff enter information such as "recommended family services" into the portal system.

Staff make a DCF report amid concerns about the safety of the infant and when prenatal exposure is a result of maternal substance use. Exposure includes prescribed medications, as clinically indicated, such as those used to treat OUD.

† ICD codes are international standards developed by the World Health Organization and are used for a variety of purposes including medical billing. See International Classification of Diseases, Ninth Revision (ICD-9).

Connecticut DCF uses de-identified data from both pathways, including maternal and infant demographic information, the type of exposure, and community type (e.g., urban, rural, suburban) to determine the total estimated number of families affected by PSE as well as how to allocate resources and identify potential disproportionalities.

There are various points, including prior to the birth (or hospital discharge), when staff can develop POSC. The POSC must include a lead provider, and the birth hospital must verify (with the developer) upon notification. Absent verification, the portal will direct the case to the child maltreatment report track.

View further details at the Connecticut State Department of Children and Families Newborn Notification Portal, which includes a CAPTA Notification FAQ, CAPTA Reporter Flow, CAPTA Portal Notification Questions, and a Portal FAQ (the Appendix also includes reporter flow, notification questions, and portal FAQ documents).

NEBRASKA

In Nebraska, all infants with PSE receive POSC documented in maternal or neonatal medical records, such as the discharge summary. Hospitals are to send the POSC to the infant's pediatric care provider. The development of the plan should involve the family who will then receive a final copy at discharge.

The state has implemented different pathways for families affected by PSE. A child maltreatment report goes to the Nebraska Child Abuse/Neglect Hotline when there's a concern for child safety (e.g., parents with SUD are not engaged in treatment). Absent child safety concerns, a CARA Notification Form goes to the state Department of Health and Human Services. Examples of when a notification is applicable include when parents are stable and engaged in MOUD with a licensed physician.

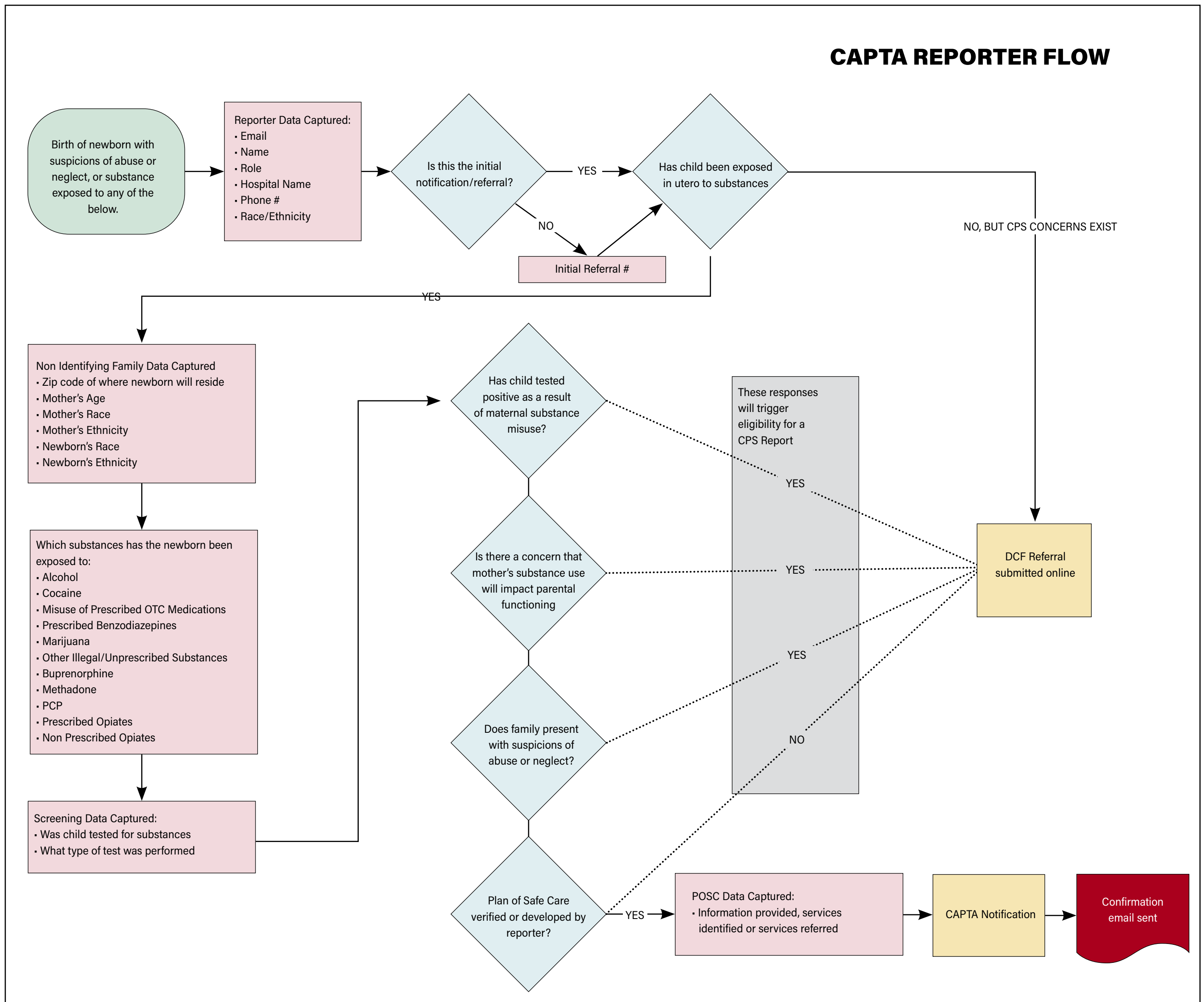
The CARA notification form collects de-identified information, including type of substance to which the infant was exposed, maternal and infant demographics, reason for the notification, existence of a POSC, and whether staff referred the family to services. Staff gather the information for data collection purposes using the CARA Notification Spreadsheet. See the notification form and spreadsheet in Appendix B or access them at Nebraska Department of Health and Human Services Comprehensive Addiction and Recovery Act (CARA) and CARA Information. See also Infants born affected by substance use or misuse and an update on Nebraska's response to the CARA letter.

NEW HAMPSHIRE

New Hampshire modified its certificate of live birth, known as the birth certificate worksheet, to include items such as prenatal exposure to opioids, stimulants, and other substances. Upon birth, the birthing center or hospital completes the worksheet. Staff de-identify and aggregate the data on prenatal exposure before submitting to CB to fulfill the CAPTA data reporting requirements on an annual basis.

All infants with PSE receive POSC in New Hampshire. The health care provider develops the POSC with the mother. Staff must complete the Plan before the family leaves the hospital. State law requires attaching a copy of the POSC to the hospital discharge instructions provided to the family. New Hampshire encourages providers to send the POSC to the infant's pediatrician at the time of discharge. State law requires providers to send a copy to the Department of Children, Youth and Families in cases of suspected child maltreatment. See New Hampshire's POSC Guidance Document.

Appendix A: Connecticut State Department of Children and Families CAPTA Reporter Flow



Appendix B: CAPTA Portal Notification Questions

CAPTA Portal Notification Questions
Reporter's Email:
Secondary Email:
Reporter's Name:
Reporter's Role:
Reporter's Hospital:
Other (name of hospital):
Reporter's Address:
Reporter's City:
Reporter's State:
Reporter's Zip Code:
Reporter's Phone:
Reporter's Race:
Reporter's Ethnicity:
Is this the initial notification/referral regarding the identified newborn?
Initial Reference Number:
Has the child been exposed in utero to substances?
Zip code of where newborn will reside?
Mother's Age:
Mother's Race:
Mother's Ethnicity:
Newborn's Race:
Newborn's Ethnicity:
Which substances has the newborn been exposed to?
Was child tested for substances?
What type of test performed?
What were the results of child drug screening?
Has child tested positive as a result of maternal substance misuse?
Is there a concern that mother's substance use will impact parental functioning?
Does family present with suspicions of abuse or neglect?
Is there a plan of safe care developed or verified by reporter?
Information provided, services identified or services referred:

Appendix C: CAPTA Portal FAQs

What is the “secondary email” for? In our conversations with hospital staff, there was an indicated need for the system to “share” the notification with more than just the reporter. We would encourage the hospitals to consider developing internal systems to allow for broader communication if needed, and if that solution was a shared email notification, the “secondary email” would accommodate that. In the absence of a more general mailbox, this option supports a second email address for another team member.

What if there are multiples born? The CAPTA notification is specific to the individual child, so separate submissions will be required.

What if the toxicological testing is pending? Should there be incomplete or pending information at the time of the referral, there is an opportunity to resubmit the information and link it to the original notification by entering the “Reference Number”, which is included for every submission and found at the top of the confirmation email.

Shouldn’t every newborn’s family have a Plan of Safe Care developed? Yes, we agree. Many of the components that are included in the POSC overlap with discharge plans that would be expected for any newborn. Newborn’s that are substance exposed may present with elevated needs and the family may have stressors that would benefit from supports or services. Your role in setting these families up for success is paramount.

What if a CPS report is made and discharge is imminent? In an effort to expedite response, if a referral is submitted within 8 hours of a scheduled discharge, the reporter should follow up with a call to the Careline. During the call you can provide your reference number which will allow the Careline screener to recover your submission and process it timely, without the need for the reporter to repeat the information.

Why can’t I advance to the next page? Progression through the portal is dependent on the completion and correct format for all required fields. Please review what you have entered.

How do I know that I am submitting a CPS Report (136)? Your answers to the questions regarding risk and safety factors for the newborn will dictate whether a CPS report is appropriate. If it is, after your completion of the CAPTA Notification information, you will be directed to the demographic page which continues into the CPS (Child Protective Services) report questions. You will receive separate confirmations upon proper submission for a CAPTA Notification and a CPS Report.

Speaking of the DCF 136, do I need to submit one after completing the portal? No, by submitting the referral online you have met your expectations for a Mandated Reporter.

On the CPS referral what does “What is the location of the child (newborn)?” referencing? This information is useful to the responding Regional Office upon acceptance of a referral to identify the location of the newborn within the hospital. Information regarding floor, department, etc., would be helpful.

What happens next? Upon completion of the CAPTA Notification, you will receive an email back with confirmation of your submission, including all the information you provided. Upon completion of a CPS Report, you will also receive a confirmation email and the Careline will review the information provided to make a determination if the concerns meet the statutory definition for the Department’s involvement. If the referral is not accepted, you will receive a Mandated Reporter letter with that information, via the email that was provided. If the referral is accepted, you can expect a call from the DCF Regional Office assigned to the referral.

We recognize that there is a great opportunity to learn from our experiences with this process and plan on making appropriate modifications as we progress. Your patience and commitment is appreciated.

Appendix D: Nebraska Comprehensive Addiction and Recovery Act (CARA) Notification Form

Nebraska Department of Health and Human Services

Comprehensive Addition and Recovery Act (CARA) Notification Form

If you suspect either child abuse or neglect, please call the Nebraska Abuse and Neglect Hotline at 1-800-652-1999.

Email or fax this form to DHHS.CARANotification@nebraska.gov or 404-328-6218. Please do not include patient identifiers.

____________________ in ____________________, NE
Hospital Name City/Town

____________________ ____________________
Child's Race Mother's Race

Please check the box next to the following criteria, if applicable:

- ☐ Mother is stable and engaged in opioid medication assisted treatment with a licensed physician.
- ☐ Mother is being treated with opioids for chronic pain by a licensed physician.
- ☐ Mother is stable and engaged in treatment for other non-opioid substance use, including alcohol, with a licensed provider, physician and/or stable recovery program.
- ☐ Infant is at risk for Fetal Alcohol Spectrum Disorder.
- ☐ Mother is engaged in substance use or misuse, (including Marijuana) that does not rise to the level of abuse/neglect requiring a report. This is up to the physicians judgement.

Plan of Safe Care:

- ☐ Plan of Safe Care for the family was completed as required by CARA.

Prenatal Exposure:

Methadone/Buprenorphine (MAT)		Other:	
Prescribed opioids for chronic pain			
Prescribed benzodiazepines		Other:	
Marijuana			
Nicotine/tobacco		Other:	
Alcohol			
Methamphetamine			

Report made to the Child Abuse/Neglect Hotline: ☐ Yes ☐ No

Referral made to appropriate service(s): ☐ Yes ☐ No

Appendix E: Nebraska CARA Notification Reporting

CARA Notification Reporting DRAFT

Email for fax this form to DHHS.CARANotification@nebraska.gov or 402-328-6218

Month/ Year	Date of Birth	Child's Race	Mother's Race	Mother is stable and engaged in opioid medication assisted treatment with a licensed physician;	Mother is being treated with opioids for chronic pain by a licensed physician;	Mother is stable and engaged in treatment for other non-opioid substance use, including alcohol, with a licensed provider, physician and/or stable recovery program;	Infant is at risk for Fetal Alcohol Spectrum Disorder;	Mother is engaged in substance use or misuse, (including Marijuana) that does not rise to the level of abuse/ neglect requiring a report. This is up to the physician's judgement.	Plan of Safe Care for the **Family** was completed as required by CARA	Prenatal Exposure to:	Report made to Nebraska Abuse/ Neglect Hotline (Yes/No)	Referral made to appropriate service(s) (Yes/No)
Infant 1												
Infant 2												
Infant 3												
Infant 4												
Infant 5												

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