Substance-Exposed Infants: Policy and Practice

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http://www.ncsacw.samhsa.gov
June 20, 2006

A Program of the

Substance Abuse and Mental Health Services Administration
Center for Substance Abuse Treatment

and the

Administration on Children, Youth and Families
Children's Bureau
Office on Child Abuse and Neglect

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
Administration for Children and Families
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Mission

- To improve outcomes for families by promoting effective practice, and organizational and system changes at the local, state, and national levels
  - Developing and implementing a comprehensive program of information gathering and dissemination
  - Providing technical assistance

Overview

- The policy context
- Some numbers
- A policy and practice framework
- The 10-State study
- State policy and practice: findings, models and implementation
- Opportunities for advancing policy

SUBSTANCE-EXPOSED INFANTS

The Policy Context

- Child Abuse Prevention and Treatment Act (CAPTA) amendments of 2003
  - Referrals of newborns identified as exposed illicit substances
  - Referrals of children birth to age 3 to Early Intervention Services
- Increasing number of pregnant women and children affected by maternal use of methamphetamines
- Research on fetal alcohol spectrum disorders and alcohol-related neurodevelopmental disorders
- Congressional caucus addressing this issue
- Proposed State legislation aimed at both fetal alcohol exposure and maternal abuse of illegal drugs

No One Agency

The SEI issue does not “belong to” any one agency, because it demands

- *comprehensive* services
- provided along a *continuum* of prevention, intervention and treatment
- at different *developmental stages* in the life of the child and family

No single agency can deliver all of these

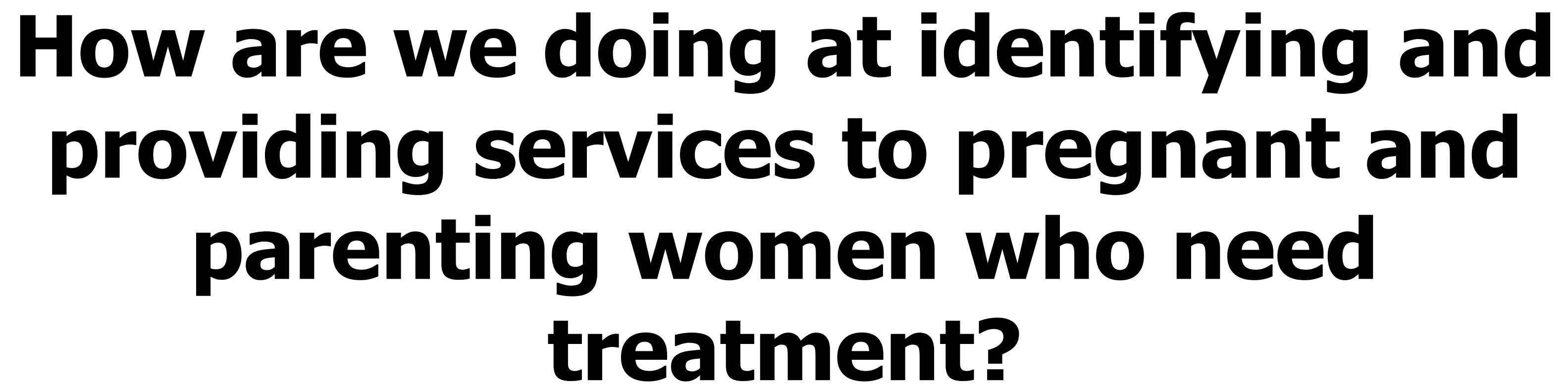
The Needed Partners

- Collaboration on SEI issues requires roles for
  - Hospitals
  - Private physicians
  - Health care management plans
  - Maternal and child health
  - Children’s and adult mental health
  - Domestic violence agencies
  - Child welfare
  - Drug and alcohol prevention, treatment and aftercare
  - Developmental disabilities agencies
  - Schools and special education
  - Family/dependency courts
  - Child care and development
  - Employment and family support agencies
  - And more…

SUBSTANCE-EXPOSED INFANTS

The Numbers

- Use during pregnancy
- Women and pregnant women needing and receiving treatment
- Substance-exposed infants


How are we doing at identifying and providing services to pregnant and parenting women who need treatment?

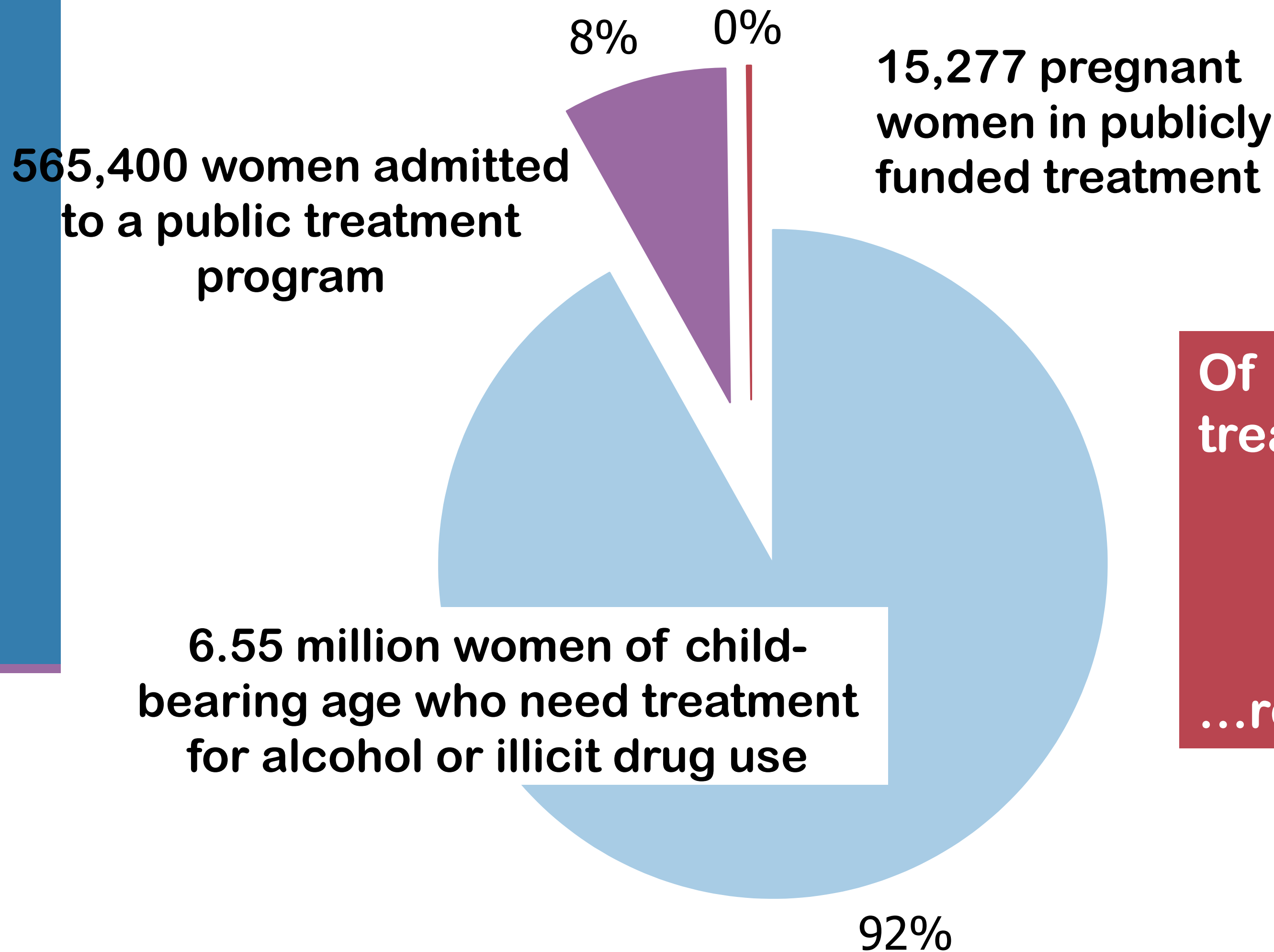
Use During Pregnancy

SAMHSA, Office of Applied Studies, National Survey on Drug Use and Health, 2002 and 2003

Substance Used (Past Month)	1st Trimester	2nd Trimester	3rd Trimester
Any Illicit Drug	7.7% women 315,161 infants	3.2% women 130,976 infants	2.3% women 94,139 infants
Alcohol Use	19.6% women 802,228 infants	6.1% women 249,673 infants	4.7% women 192,371 infants
Binge Alcohol Use	10.9% women 446,137 infants	1.4% women 57,302 infants	0.7% women 28,651 infants

Women and Pregnant Women in Treatment

- **There are four million births annually, and six and a half million women of child-bearing age who need treatment**



Of those who need treatment…

9.7% of men

7.4% of women

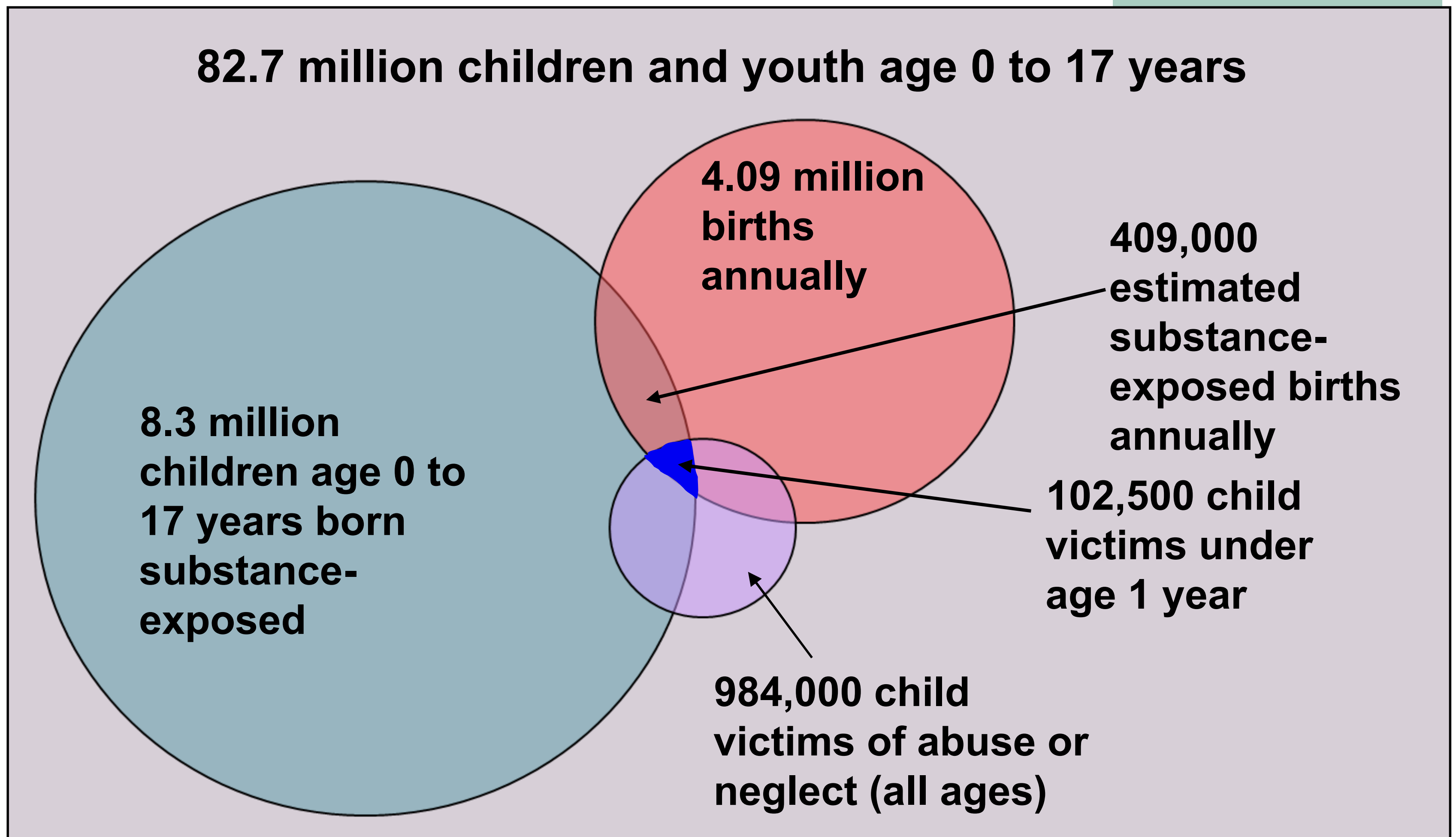
…receive treatment

Number of Substance-Exposed Infants

Estimates are that 10-11% of all newborns are prenatally exposed to alcohol or illicit drugs; this translates to:

- An estimated 400,000-480,000 substance exposed births nationwide last year
- A cumulative 7.3 million of the 73 million children ages 0 to 17 years old

A Graphic View



HOW ARE WE DOING AT IDENTIFYING SUBSTANCE-EXPOSED INFANTS?

Most go home…

75-90% of substance-exposed infants are undetected and go home.

Why?

- Many hospitals don’t test or don’t systematically refer to CPS
- State law may not require report or referral
- Tests only detect very recent use

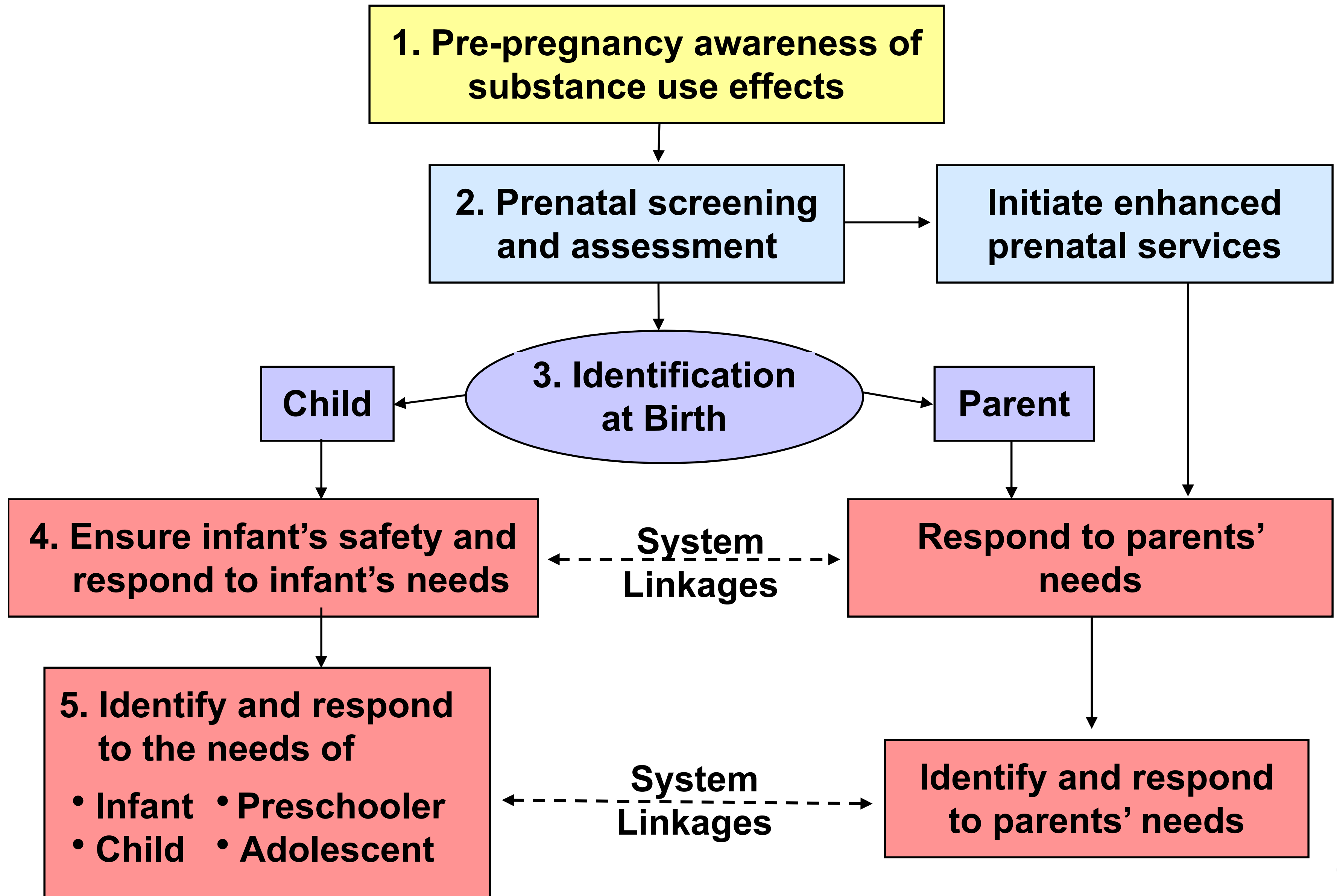
A POLICY AND PRACTICE FRAMEWORK

The Five Points of Intervention

- Pre-pregnancy and public awareness
- Prenatal screening and support
- Screening at birth
- Services to infants
- Services to parents

- So—the birth event is one of several opportunities to make a difference, not the only one

Policy and Practice Framework: Five Points of Intervention



THE 10-STATE STUDY

The 10-State Descriptive Study

- Purpose was to better understand and describe States’ policy regarding substance exposed infants
- Coordinated with AIA study
- Reviewed Federal and State legislation
- Reviewed State publications
- Reviewed other national assessments of substance exposed infant and family issues

The 10-State Study

- Selected 10 States for in-depth interviews based on efforts in one or more of the first points of intervention
  - California, Hawaii, Illinois, Maryland, Massachusetts, Minnesota, Rhode Island, South Carolina, Virginia, and Washington
- Developed interview guide based on the policy and practice framework five points of intervention

What Kinds of Policy

- Federal laws
- State legislation
- State regulations and guidelines
- State budget allocations
- State interagency bodies with policy responsibilities
- The implementation of policy
  - Respondents' view of what happens in the field
  - Reviewed State and national data that may indicate how policy had been implemented

The 10-State Study

- Conducted 1- to 2-hour interviews as an open-ended guided discussion
  - Contacted the Women's Treatment Coordinator in each State
  - Identified officials from several departments across agencies
    - 3 to 4 respondents in each State

THE 10-STATE STUDY

State Policy, Practice and Models

- 10-State Study
  - Findings
  - Models
  - Implementation
- Within the Five Points of Intervention
  - Pre-pregnancy and public awareness
  - Prenatal screening and support
  - Screening at birth
  - Post-natal services to infants
  - Post-natal services to parents

1. Pre-Pregnancy

- Findings
- States have developed public education campaigns
  - Warning signs at point of sale
    - 3 out of 10 study States
    - 37% of all States
  - Warning signs at other venues
    - 3 out of 10 study States
    - 24% of all States

1. Pre-Pregnancy

- Findings
- States have worked with institutions of higher education in disseminating this message
- Federal "Drug Free Schools and Communities Act Amendments of 1989"
  - Universities and educational institutions that accept federal funding must notify their employees and students that use of alcohol during pregnancy may have detrimental effects on their children
  - Model: University of Massachusetts

1. Pre-Pregnancy

- Implementation
- Rates of first trimester use suggest that the message is not getting through to a critical group of pregnant women
- Use during 1st Trimester
  - 7.7% women used any illicit drug (315,161 infants)
  - 19.6% women used alcohol (802,228 infants)
  - 10.9% women engaged in binge alcohol use (446,137 infants)

SAMHSA, OAS, National Survey on Drug Use and Health, 2002 and 2003

2. Prenatal Screening and Services

Findings

- All States had some prevention efforts and some form of prenatal screening efforts
  - Model: Washington State has developed detailed guidelines for prenatal screening, and a quality improvement effort that seeks "universal screening" for substance use
  - Some jurisdictions within States had screening policies
- All States gave pregnant women priority status in entering treatment, in accord with federal requirements

2. Prenatal Screening and Services

Implementation

- No States *require* prenatal screening for substance abuse
- Medicaid funds 37% of births, but it is typically not used for encouraging nor requiring screening programs

2. Prenatal Screening and Services

Implementation

- Referrals of pregnant women to treatment and progress in treatment are not monitored on a Statewide basis
- Wait lists persist in some States—particularly for residential care
- Admissions of pregnant women are a very small percentage of total admissions

3. Screening and Testing at Birth

Findings

- Policies on screening at birth are generally not at the State level
  - Local hospital policy dictates screening practices such as who is screened
- Reporting requirements
  - 5 of 10 study States require reporting to CPS at birth
    - 2 study States require as mandated reporters
  - 37% of all States
  - Recent legislation proposed or enacted in some States has expanded requirements for referrals when drug exposure is detected -- AR, CO, LA, NV, WA

3. Screening and Testing at Birth

Findings

- Defining substance exposure as evidence of child abuse or neglect
  - 7 out of 10 study States
  - 40% of all States
  - Policies vary for different substances
    - "controlled substance," "addictive drug," "non-prescription, controlled substance or signs of fetal alcohol syndrome," "cocaine, heroin or a derivative thereof"
- FASD issues have received new attention in some States – HI. MD, MN, ME

3. Screening and Testing at Birth

Implementation

- Hospitals' policies vary widely with few standardized protocols that are consistently implemented
- States do not monitor screening and referrals
  - Hospitals do not usually provide CPS agencies with totals of screenings at birth, results of tests, or number of referrals made to CPS
- Detection of and response to FAS and FASD is inconsistent in policy and practice

4. Post-Natal Services to Infants and Children

Findings

- Early intervention policies and process for referrals to IDEA are still emerging
  - Two out of 10 Study States (MA and RI) have strong links between IDEA referrals and SEIs in child protective service agencies

4. Post-Natal Services to Infants and Children

Implementation

- Too early for the 10 study States to have data on increased referrals due to CAPTA/IDEA changes
- Child welfare developmental assessments are not consistently performed for SEIs or for older children of substance abusers who may be prenatally-exposed but entered child welfare at older ages

4. Post-Natal Services to Parents

Findings

- Some States have supplemented federal funding set-asides for treatment for pregnant and parenting women
  - 5 of the 10 study States
  - 37% of all States
- Strong models of family-centered services have been developed

4. Post-Natal Services to Parents

Implementation

- Significant data gaps exist
  - TEDS requires "pregnant at admission" but not "parenting"
- Capacity of programs is not sufficient to serve all those in need of treatment for women and infants

States' Coordination Efforts

Findings

- All study States have perinatal councils or other coordinating bodies that address SEI issues
  - IDEA interagency councils
  - Women's treatment interagency councils
  - Early childhood coordinative councils
  - Interagency child welfare reform bodies

States’ Coordination Efforts

Implementation

- None of the study States have an interagency process to monitor data, effectiveness or outcomes across agencies

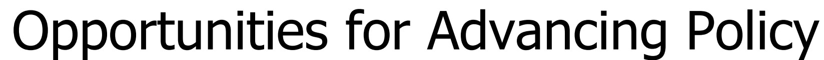
States’ Coordination Efforts

Implementation

- Information gaps make tracking progress difficult
  - Prevalence data gaps
  - SEI referral data gaps
  - Mothers treatment referral data gaps
  - Treatment outcomes data gaps
- Funding comprehensive services demands skillful efforts to access multiple funding sources; few States have current inventories of available funding

Summary

- These 10 States are responding to the SEI problem and the 2003 CAPTA changes with some strong programs
- None of the study States have developed policy at each of the five points of intervention for mothers and infants
- State policy implementation occurs across a diverse set of agencies requiring extensive coordination



SUBSTANCE-EXPOSED INFANTS: POLICY AND PRACTICE

The barriers to collaboration on SEI issues

- Fear of flooding: “there are no treatment programs,” “we’ll get inappropriate referrals”
- Concern about punitive responses: if we report, removal of child will result
- Basic lack of information about other agencies’ services and policies
- Different missions: child safety, parents’ services needs, family stability

How could a state self-assess its current collaboration on SEI issues?

- Review the data—what do we know, where are the gaps, how can info systems be improved?
- Review all five levels of policy: inventory current resources in each of the five areas
- Review the results in each area—how do we measure progress or success?
- Review who is at the table and who is missing
- Review the options for a strategic plan across agencies with shared outcomes

An example: self-assessing current prenatal services

- What are current practices of physicians in screening [are 4Ps Plus or other brief tools used?]
- How many Medicaid births [37% nationally] are screened?
- How many referrals are made to treatment from prenatal screening? What %?
- What estimates do we have for current prenatal exposure—how do #s of referred women compare to the estimated need?
- What is the treatment gap and how does it compare to total of women entering treatment—is there an issue of priorities?

A second example: self-assessing screening at birth

- What are current hospital practices? How many screens, how many are positive, how many referrals?
- What happens after a CPS referral: a CPS report should *begin* the process of intervention
- What other services are available to parents? How many parents enroll? How many complete?
- What are the "handoffs" to family support, home visitation, CWS "front-end" voluntary services, CWS reunification?
- Who case manages these services?

The Message of the Missing Numbers

- Sherlock Holmes: the case of the dog that didn't bark
- Sometimes it is what *doesn't* happen that matters most—lacking the numbers to measure a problem may *be* the problem
- Caring enough to count is the heart of accountability

Why are substance-exposed births important?

- Though a small percentage of CWS cases, these children are disproportionately affected by many lifetime conditions
- Prenatal exposure to alcohol is the leading cause of mental retardation
- Special education classrooms contain a disproportionate number of children who were prenatally exposed to drugs.[3,4]
- SEBs require a higher level of public spending than many other target groups

An Ethical Perspective on SEBs

- Weighing the value of reducing lifetime risks to an innocent child through intervention vs. a woman's right to privacy
- The likelihood of inadequate prenatal care if screening is a deterrent
- The possibility of a punitive rather than comprehensive response
- The long-term costs to taxpayers of SEB consequences

An example of the ethical tradeoffs:

- 61% of physicians fear that criminal charges would be a barrier to women receiving prenatal care, but
- More than half support legislation allowing removal of children from any woman who abused alcohol or drugs.

Parental Substance Use – It's Not Just About Moms

- Among parents living with their children, fathers are more likely than mothers to abuse or be dependent on alcohol or an illicit drug (SAMHSA, 2003b)
- Very little is known about the dynamics of fathering in the context of chronic drug abuse
- Men with SUDs typically begin fathering children after onset of serious drug abuse. One study showed:
  - 63% of fathers, compared to 33% of mothers, were using drugs at time of birth of oldest child
  - Fathers had been using drugs regularly for 14.4 years, compared to 9.5 years for mothers (McMahon et al., 2005)

Issues for State Consideration

The Role of Alcohol

- The CAPTA amendment does not specifically address alcohol exposure
- States may have available data on fetal alcohol spectrum effects that can be used to assess incidence of FAS and related conditions

Issues for State Consideration

Toxicology Screens

- Blood tests only identify patients with long-term use in whom secondary symptoms have occurred
- Timing – Urine toxicologies identify only recent use (within the past 24-72 hours)
- Urine tests are not reliable for alcohol
- Cost of toxicology screening
  - $8-$80 depending on type of test – blood vs. urine, extent of drug panel, sensitivity, cut-off level, etc.

Issues for State Consideration

Testing/Identification

- Voluntary testing vs. universal testing vs. testing based on valid screening and assessment practice
- Given the current bias in testing, Universal testing is the only unbiased approach
  - raises issues of privacy and intrusiveness
  - must consider cost, false positives and confirmations of those tests
- "Upstream" prenatal screening is much preferable, and done correctly, is just as accurate or more so

Issues for State Consideration

The Role of Dependency/Family Court

- A significant number of dependency petitions are filed in response to positive tox screens
  - Many states and localities lack data on removals based on SEB; the court can upgrade its information systems to require this data
- The court is a key collaborative partner—but it needs to be a true partner, aware of the roles of the other players and willing to monitor its own outcomes as part of an annual accountability review

The Policy Questions

- Can a pregnancy screening (like 4Ps) be the trigger for "upstream" services and referral to treatment?
- Can a mandated SEB report to CPS be the trigger for "downstream" follow-up services to child and parent(s)?
  - Home visiting, family support, parenting skills, child development and developmental screening
- Is our interagency collaboration strong enough to guarantee that these results will happen and be monitored over time?

Opportunities for Advancing Policy

- CFSR review II—spotlight on the child welfare system's SEI reunification outcomes
- Federal treatment information system changes
- Monitoring of child and family service state plans

Opportunities for Advancing Policy

- IDEA referrals under CAPTA
- Renewed focus on school readiness issues
- Using Medicaid funding of births to leverage screening efforts

Conclusions

Four key policy challenges:

- There are many opportunities *before and after the birth event* to intervene—a balanced policy would address all five stages of the SEI problem
- To address all five stages, States need much stronger coordination that monitors progress across multiple agencies

Conclusions

Four key policy challenges:

- States don’t track SEIs and treatment for mothers well enough to measure whether they are making progress on the problem or to justify additional resources
- Treatment programs do not admit enough pregnant and parenting women in comparison to those who need treatment services

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