Implementation of CAPTA as a Policy and Practice Tool to Reduce the Impact of Prenatal Alcohol Exposure: *Points of Agreement*

On August 1-2, 2011, a group of representatives of national organizations concerned with children affected by prenatal exposure to alcohol and illicit drugs met in Chicago to develop a statement focusing on the implementation of the Child Abuse Prevention and Treatment Act (CAPTA), as amended in 2010. The provisions of CAPTA with which the group was most concerned were (1) the referral of drug or alcohol-affected newborns to child welfare agencies, with alcohol exposure and a reference to Fetal Alcohol Spectrum Disorders (FASD) included for the first time, and (2) the referral of children 0-2 in a substantiated child welfare case to a Part C early intervention agency for developmental screening.

The group's discussion of CAPTA and FASD issues took place in the context of a much wider concern for prenatal substance exposure, which was the basis for the original CAPTA legislation in 2004. The group emphasized that FASD is not a diagnostic term, but a broad description of a range of effects due to prenatal exposure to alcohol. The ten principles that follow represent the points of agreement in the discussions among the representatives attending the meeting. Guiding the development of these principles is our unanimous agreement that substance use in pregnancy is a public health issue. We strongly oppose referrals to the criminal justice system rather than to appropriate treatment. We also oppose targeted screening with toxicological testing at birth, which can be subject to bias and can trigger punitive responses in some states and localities. These approaches make it more difficult to get pregnant and parenting women the treatment they need and affects the ability to access early intervention services for their children.

The statement does not represent the official positions of any of the participants' organizations; it is the intent of the group to circulate this document among their organizations and several others that work in this field. The representatives who met in Chicago in August fully recognize there is a diversity of perspectives on the issues of prenatal exposure, prenatal screening, and other issues touched on in this document, and the group seeks wide review and consideration of these thoughts.

Two additional points were also underscored during the discussions:

- the major challenges facing state and local governments in considering how to respond to an issue such as CAPTA in the midst of great fiscal uncertainty and
- the challenges facing federal agencies in playing their needed oversight role with limited resources and multiple demands.

The Principles

1. States currently are inconsistent and uneven in their implementation of the CAPTA provision to refer substance-exposed newborns to child protective services (CPS) for prenatal exposure to alcohol. Likewise there is inconsistency in the referral of substantiated 0-2 cases, many of which involve infants and toddlers affected by prenatal alcohol exposure, from CPS to Part C agencies. We believe that this is a missed opportunity to give needed attention to FASD issues as intended by Congress in the 2010 amendments.

   ***Recommended Action*:** We urge HHS (including SAMHSA, MCHB, ACF and others) and the US Department of Education to work together to provide financial incentives and formal guidance in the form of a Program Instruction to states to enhance effective implementation of these requirements, including development of a model for the Plan of Safe Care that states *are required by the CAPTA legislation* to develop in every referred case.[i]

2. Congress has required that states track and enumerate prenatal exposure and developmental screening in response to prenatal exposure. Most states do not identify, collect, or report adequate data on prenatal exposure and referrals to and enrollment in early intervention programs for prenatally exposed infants and younger children.

   ***Recommended Action*:** We recommend that HHS and the US Department of Education provide financial incentives to states to improve data collection, child outcomes, and the rate of cases receiving appropriate referrals.

3. HHS, through HRSA and ACF, must assure that use of the term FASD, as referenced in the CAPTA amendments of 2010, is clarified to health providers and staff in relevant agencies in all states.

   ***Recommended Action*:** We recommend that states, using the most advanced strategies and guidelines for defining the diagnostic components within FASD, should incorporate existing knowledge into state practice and communicate with all relevant clinicians, hospitals, and other providers of care to children birth to two years.

4. Knowledge of FASD, its identification and strategies for treatment are lacking among health, early learning, family and child welfare professionals who come into contact with children who have been affected by prenatal alcohol exposure.

   ***Recommended Action*:** We recommend that states provide evidence-based training[i] to personnel across multiple domains, agencies, and disciplines to educate them on issues related to prenatal alcohol exposure and the diagnosis of fetal alcohol syndrome and the broad spectrum of associated disorders that fall within FASD. Recognizing that there are no guidelines for diagnosing Alcohol Related Neurodevelopmental Disorder (ARND) within the newborn or early infancy period, we urge the development of such guidelines.

5. A wide range of disciplines and professions are involved in the care and oversight of children affected by prenatal exposure to alcohol and illicit drugs.

   ***Recommended Action*:** We urge that Title IV-E-supported training for judges, attorneys, and court staff, as well as CPS staff, foster and adoptive parents, and others included under the federal Fostering Connections Act training provisions should address issues related to FASD. Reflecting the recent amendment to CAPTA requiring the training of attorneys for children, *guardians ad litem*, and Court Appointed Special Advocates on early childhood development, we urge that such training also include content on FASD.

   HHS should encourage, in new applications under the *Regional Partnership Grants to Assist Children Affected by Parental Substance Abuse* that were reauthorized in the 2011 reauthorization of the Promoting Safe and Stable Families Program, the use of multidisciplinary approaches to addressing FASD.

6. Within the context of the 2010 CAPTA legislation, screening newborns and infants for prenatal exposure to drugs and alcohol should not be defined as a single event using a single tool, but as a continuing process that includes prenatal screening of the mother accomplished through the use of standardized and validated screening instruments, not through toxicological testing at delivery.[ii]

   ***Recommended Action*:** Following birth, we urge developmentally appropriate screening of all newborns, infants and young children. This screening should take place as a component of primary care, ideally as part of a medical home. For infants and children in foster care, this should be consistent with the Fostering Connection's Act's promotion of the medical home concept. *Such screening should also be coordinated with other screening requirements, including EPSDT and Early Head Start.*

7. Extensive research has documented the benefit of prenatal screening, brief interventions, and family-based treatment in reducing the effects of prenatal substance exposure.

   ***Recommended Action*:** The Children's Bureau and HRSA should issue a joint announcement to states regarding the importance of prenatal screening coupled with brief intervention strategies and longer term family-based treatment as needed to reduce the harms associated with prenatal substance use.

   ***Recommended Action*:** We urge states to implement policies, including full utilization of Medicaid reimbursement, that ensure pregnant women receive information about the harm of alcohol use in pregnancy and that provide for universal screening of pregnant women utilizing evidence-based instruments and priority access to substance abuse treatment for pregnant and parenting women. *Insurance carriers should be urged to include prenatal substance use education and counseling as a covered benefit in all prenatal packages*

8. There are insufficient data that document the cost effectiveness of screening, brief intervention, and treatment that are linked to primary prenatal care.

   ***Recommended Action*:** Additional research should be supported by HHS that will increase evidence of the cost savings across systems that result from *evidence-based* early identification and early intervention for infants affected by prenatal substance exposure.

9. There are several other major policy and practice issues that require attention and revision that would support CAPTA's provisions regarding prenatal substance exposure:

   Recommended Action: Federal agencies are urged to address these issues--

   A. The impact of the Affordable Care Act as it relates to the prevention of substance use in pregnancy; maternal substance abuse screening, diagnosis, and treatment availability; and enhancing access to services for their infants through early identification and diagnosis
   B. Incorporation of substance use screening and intervention within the Maternal, Infant, and Early Childhood Home Visiting Program
   C. Role of state Early Childhood Advisory Councils (required under the Head Start reauthorization) in recognizing and addressing the impact of prenatal substance exposure on children served by federally supported early childhood programs
   D. Utilization of prospective new waivers under Title IV-E to promote FASD diagnosis and early intervention and access to family treatment
   E. Examination of the barriers under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) – real and misperceived – that inhibit information sharing related to prenatal substance exposure interventions*; this information should be clearly explained and available to all providers*
   F. Modification of the *Child and Family Services Review* (CFSR) process to measure state compliance with the CAPTA provisions related to identification and referral of substance-exposed infants and children
   G. Encouragement of states, and HHS, to support new Child Welfare Demonstration Projects pursuant to the Child and Family Services Improvement and Innovation Act of 2011 that will address services to children with FASD.
   H. Modification of eligibility requirements for IDEA Part C and Part B to encompass children at risk for school failure due to prenatal substance exposure.

Supporting Information

CAPTA language as amended in 2010

State Plans shall contain assurances that there is a state law or statewide program that includes:
* * *
"(b)(2)(A)(ii) policies and procedures (including appropriate referrals to child protection service systems and for other appropriate services) to address the needs of infants born *with* and identified as being affected by illegal substance abuse or withdrawal symptoms resulting from prenatal drug exposure, *or a Fetal Alcohol Spectrum Disorder,* including a requirement that health care providers involved in the delivery or care of such infants notify the child protective services system of the occurrence of such condition in such infants, except that such notification shall not be construed to—

(I) establish a definition under Federal law of what constitutes child abuse *or neglect;* or
(II) require prosecution for any illegal action.

(iii) the development of a plan of safe care for the infant born and identified as being affected by illegal substance abuse or withdrawal symptoms, *or a Fetal Alcohol Spectrum Disorder*"

Annual state data reports—new language added in 2010 CAPTA amenments

''(16) The number of children determined to be eligible for referral, and the number of children referred, under subsection (b)(2)(B)(xxi), to agencies providing early intervention services under part C of the Individuals with Disabilities Education Act (20 U.S.C. 1431 et seq.).''

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[i] ACOG emphasizes that any alcohol use during pregnancy or the infrequent use of controlled substances early in pregnancy is subject to reporting to authorities during pregnancy or at birth. In their view, this reporting will quickly result in non-disclosure to the provider by pregnant women, who will then miss the education and counseling they require. ACOG further emphasizes that most pregnant women who use alcohol and THC are not dependent and do respond to provider intervention.

In response, members of the group noted that there is no safe level of alcohol use in pregnancy and that there is wide agreement that referrals should be the basis for supportive services and intervention, **and not formal reporting of maltreatment**, as the CAPTA legislation makes clear that what should be made is a *referral or "notification" for development of a plan of safe care with the delivery of services,* and not a report of abuse or neglect.

[ii] ACOG notes that the AAP is developing a comprehensive tool kit for child health providers to guide in the recognition and assessment of FASD. This is a CDC funded project. Contact point is Faiza Khan- fkhan@aap.org. ACOG adds: "We agree that the use of a validated maternal screening instrument and not toxicology is important, however if toxicology is used, we urge that maternal consent, or at least assent, is obtained. The mother needs to understand how this screening will be used."

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