



FASD **SYMPOSIUM**

Part 2

Today's Presenters



Erin Olson, Ph.D

*Licensed psychologist and professor at
University of Washington*



Julie Kable, Ph.D

*Professor at Emory University
School of Medicine*



Delancy Allred, MPA

*Director of Public Policy at the Autism Society
of America*



Erin Ingoldsby, Ph.D

*Director of Evaluation at James Bell
Associates and clinical psychologist*



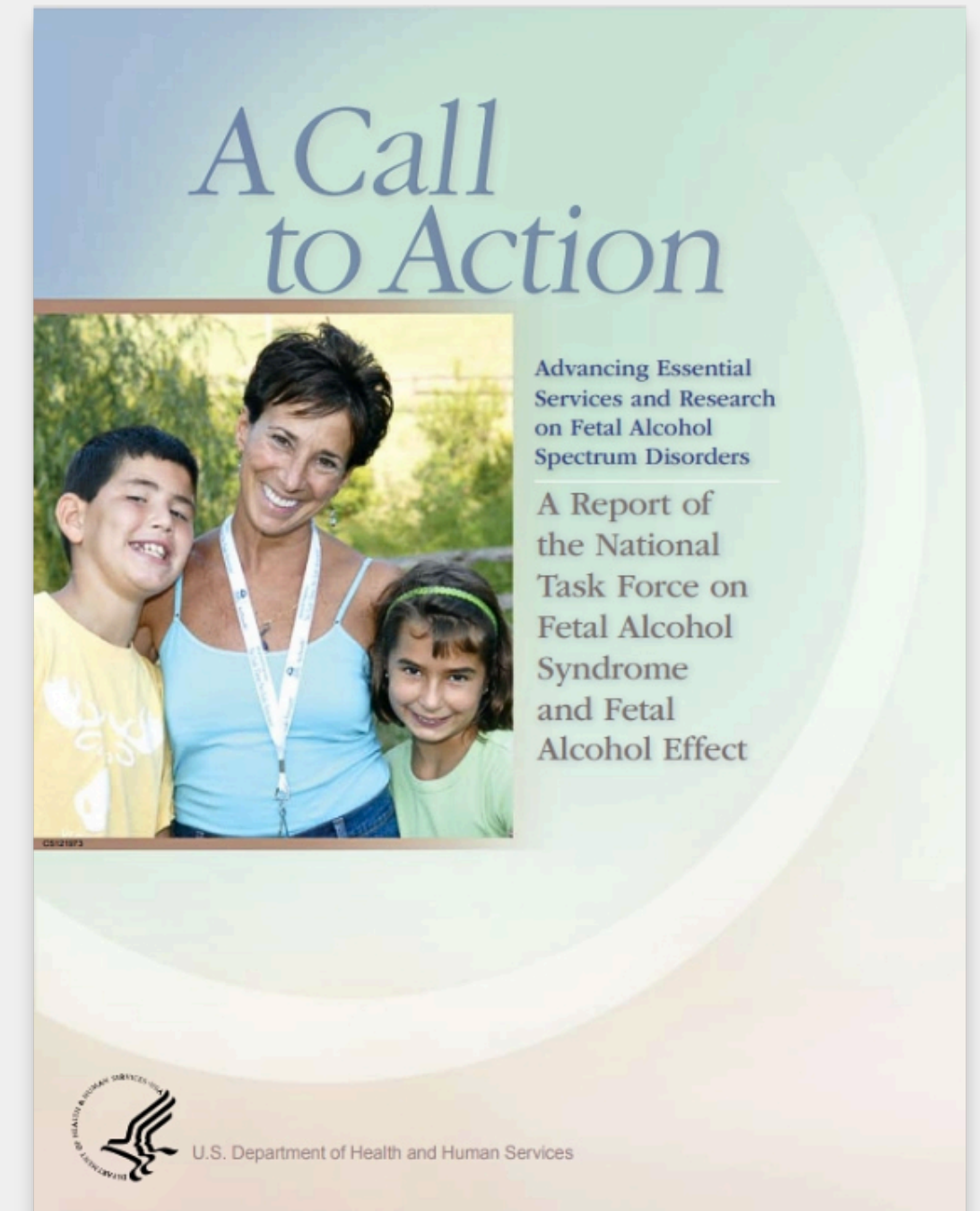
D. Crystal Coles-Quander,
Ph.D, LCSW

*Senior Research Associate at James Bell
Associates*

Task Force Recommendations

From 2009 FASD Task Force Report "**A Call to Action: Advancing Essential Services and Research on FASD**"

- Report for federal, state, and local agencies, researchers, clinicians, family support groups, and other partners on actions needed in FASD research, policy, and practice
- 10 recommendations total



2026 Symposium, Part 2

Improve access to diagnosis by standardizing procedures and enforcing universal screening.



Enhance agency collaboration through shared leadership, transparent objectives, and coordinated efforts with living experience and communities.



Make FASD eligible for government support and services.



Increase research about diagnosis, living experience, and effective interventions.



Promote a continuum of care for individuals with FASD that is evidence-based, lifelong, and reduces stigma.



Encourage professional education on FASD.



Improve tracking of prevalence and support needs.



Promote a continuum of care for families and caregivers affected by FASD.



Recognize grassroots efforts focused on FASD as powerful agents of change.



Maintain a national forum involving parents, advocates, professional organizations, and experts.



Goals of TODAY:

- Learn about the supports and services outlined in the 2009 Recommendations
- Engage as a community to co-create a vision for collaboration that centers living experience





Data Collection

- The Symposium is focused on collecting **qualitative data** through a scientific process
- Today, data will be collected through **individual submissions through Slido**

YOU
are the
experts!



**Make your voice heard by
completing the data
collection opportunities.**

Today's Focus



Coding & Billing



Diagnosis
& ND-PAE



IDEA



CAPTA

Making Sense of Cross-Discipline Crosstalk



A Little History &...

...A Whole Lot of Acronymns

ICD
1893

AMA CPT
1966

ICD-10
1989

TODAY
2026

WHO
1948

CMS
HCPCS
1978

HIPAA
1996

APA DSM
1952

DSM-III
1980

Diagnostic & Billing Standardization (HIPAA)

- Current State of US:
 - ICD-10-CM
 - APA DSM-5-TR
 - ICD-10-PCS
 - AMA CPT-4 (annual)
 - CMS HCPCS
- WHO ICD-11 (2022)



Diagnostic Code Crosswalk: Considerations

- 01** Discipline of provider influences diagnoses and diagnostic codes
 - Medical and developmental providers
 - Mental health providers
- 02** Timing of diagnoses impacts feasibility of assessing some domains of development
- 03** ICD-10-CM coding system labels may not match the diagnostic term



Just to Add a Little More Diagnostic Complication...

Interdisciplinary (Medical)

- Fetal Alcohol Syndrome (FAS)
- Partial Fetal Alcohol Syndrome (pFAS)
- Alcohol-Related Neurodevelopmental Disorder (ARND)
- Static-Encephalopathy, Alcohol Exposed (SE-AE)
- Neurodevelopmental Disorder, Alcohol Exposed (ND-AE)
- Alcohol-Related Birth Defects (ARBD)

Single Discipline (Psychological)

- Neurobehavioral Disorder associated with prenatal alcohol exposure (Conditions for Further Study)
- Other Specified Neurodevelopmental Disorder associated with prenatal alcohol exposure (F88)

AAP FASD Diagnostic Coding Guide (2022)

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



CODING FOR FETAL ALCOHOL SPECTRUM DISORDERS

Listed below are the most commonly used codes applicable to FASD patient care.

Code	Description
<i>ICD-10-CM</i>	
Primary Diagnosis	
P04.3	Newborn affected by maternal use of alcohol (Excludes Fetal Alcohol Syndrome)
Q86.0	Fetal alcohol syndrome (dysmorphic)
F06.30	Mood disorder due to known physiological condition, unspecified
P00.4	Newborn affected by maternal nutritional disorders
P01.9	Newborn affected by maternal complication of pregnancy, unspecified
G93.49	Encephalopathy, other (static)
G96.8	Other specified disorders of central nervous system
G96.9	Disorder of central nervous system, unspecified

Other Diagnostic Areas

- Facial Features
- Growth
- Development
 - Language
 - Motor
 - Cognitive/Learning
- Mental Health
 - Mood/Anxiety
 - Trauma/Stressor-Related
- Medical
 - Sleep
 - Seizure
 - Gastro-intestinal
 - Cardiac
 - Other Exposures



BILLING CODES:

For Procedures Related to FASDs

- Billing codes are required for service reimbursement
 - Billing codes are often restricted to specific providers
- MUST demonstrate **Medical Necessity**
 - #1 reason for denial is due to missing or incomplete documentation
- Recognized codes and reimbursement rates vary widely by state
 - Some codes are incompatible with a diagnostic code

Billing Codes for Procedures

Medical Codes

Outpatient codes are based on patient status (new vs returning) and level of care:

- Number and complexity of problems addressed
- Amount and/or complexity of data reviewed and analyzed
- Risk of complications and/or morbidity or mortality
- Time-based add-on available

Examples:

- 99205=New patient Level 5 (highest level of care)
- 99417=Prolonged service

Related to FASDs

Psychiatric Codes

Evaluation:

- 90791=Diagnostic Interview (90m)
- 96130/1=Evaluation
- 96136/7=Test Administration
- Addt'l codes for psycholmetrists

Therapy:

- 90832/34/37=30/45/60m Individual Psycholtherapy
- 90846/47=Family Therapy w/o Patient/with Patient
- 90849=Multi-Family Therapy Group

Add-Ons

- 90785=Interactive Complexity
- 90839/40=Crisis



Continued Advocacy Needed...

- Procedures exist to petition for new procedure/service codes vis CMS and AMA
- Local codes exist and advocating with state health care authority can establish coverage
- If coverage is denied... **Appeal, Appeal, Appeal!**
 - Third time is (usually) the charm

Thank You





Data Collection

**What do you suggest we do next with this recommendation?
Tell us on Slido.**

Now is the time to make your voice heard!

Slido submissions are our main "data buckets" for this recommendation.



Slido #1235430



Data Collection

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Slido #3827337



**Autism
Society**

National FASD Impact Week 2026

Education Update

Overview of IDEA

The Individuals with Disabilities Education Act (IDEA) is the federal law that protects the rights of students with disabilities.

- Eligibility
- Free Appropriate Public Education (FAPE)
- Least Restrictive Environment (LRE)
- Individualized supports and services
- Parent and student rights
- Federal-state partnership

Overview of Sec. 504

Section 504 of the Rehabilitation Act is a federal civil rights law that protects people with disabilities from discrimination.

- Applies to federally funded programs
- Broader definition of disability
- Equal access
- Reasonable accommodations
- 504 Plans
- Civil Rights Protections

Role of the Federal Department of Education (ED)

- Sets a national framework
- Distributes federal funding
- Supports families and educators
- Monitors state compliance
- Provides technical assistance



Current Climate in D.C.



Challenges at ED

- Office for Civil Rights (OCR): 7 of 12 regional offices closed; significant staff reductions
- March Executive Order: Directed steps toward closing the Department of Education
- Workforce reductions: RIFs and layoffs across Education and HHS
- Interagency agreements announced: OCR functions moving to the Department of Justice
- OSERS functions moving to HHS
- OSERS leadership: Interim Assistant Secretary resigned

Challenges in Congress

- Mixed views on changes to ED
- Bipartisan efforts to reverse or limit some interagency agreements
- Education legislation moving forward: READ Act
- 21st Century Dyslexia Act
 - Dyslexia Act: Would create a new IDEA disability category, raising questions about whether changes to IDEA are appropriate given the current federal landscape and whether dyslexia is already addressed through the Specific Learning Disability (SLD) category

Special Education Advocacy in a Changing Landscape

The federal landscape is changing. Agency structure, staffing, oversight, and

- implementation are all in transition.

IDEA and Section 504 protections remain important federal rights.

- State and local advocacy matters. Federal changes can have significant
- implications for how services are delivered on the ground.

Congress will remain an important part of the conversation, particularly as

- legislation and funding decisions move forward.

The 2026 midterm elections will shape the next Congress and the direction of

- federal education policy.

There is still an important role for advocates: educating policymakers, sharing

- families' experiences, monitoring implementation, and advocating for effective policy.



**Autism
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Thank you.



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Slido #2999202

Key Considerations for The Child Abuse Prevention and Treatment Act (CAPTA) & FASD

FASD & National Impact Week

September 28, 2026



What is CAPTA?

The Child Abuse Prevention and Treatment Act (CAPTA), originally enacted in 1974, establishes national definitions regarding child abuse and neglect and assigns certain responsibilities to the federal government, particularly relating to data collection and technical assistance. It also authorizes funding to public agencies and nonprofit organizations that undertake activities to prevent, assess, investigate, prosecute, and treat child abuse and neglect.

Why does CAPTA matter for FASD?

- CAPTA expressly includes infants affected by a Fetal Alcohol Spectrum Disorder within the federal substance-exposed infant framework.
- In 2016, Congress amended CAPTA; this amendment requires the development of a Plan of Safe Care (POSC) for an infant born with and identified as being affected by substance abuse, withdrawal symptoms, or an FASD to ensure the safety and well-being of infants
- CAPTA is broader than a reporting requirement: it links identification to notification, assessment, POSC, services, monitoring, and data.
- CAPTA requires states to report annually on the development of a POSC infants born with an FASD

What are states actually spending CAPTA funding on?

State CAPTA Funding Examples

- **Organization to lead statewide coalition** on SEN and its workgroups – including a FASD Awareness Workgroup
- **Staff position** inside the CW division overseeing POSC, coordination with programs, trainings, and advises counties, reporting to CAPTA Administrator
- **Facilitation for POSC strategic planning**– drafting three-year roadmap
- **Complex case consultations** program (PSE qualifies as type)

State CAPTA Funding Examples

- **Notification/referral infrastructure** — New Mexico's CARA Navigator program:
 - CAPTA funds maintain a statewide portal used by all licensed birthing hospitals and several Medicaid MCOs to track POSC development, plus ongoing training for the CARA Navigator staff who convene multidisciplinary teams
- **Provider training/consultation** — ongoing education for hospital staff and CPS on mandatory reporting distinctions, and trauma-informed engagement with families
- **MDT convening and monitoring** — funding the actual multidisciplinary team (MDT) process required to build and monitor POSCs, plus the state-level monitoring of whether local entities are delivering the referred services.
- **Data systems** for the federally-required annual reporting on identified infants, POSC completion rates, and referral/service delivery — this reporting is itself a significant driver of what states build with CAPTA money, since they have to demonstrate monitoring capacity.

State CAPTA Funding Examples

- **State-specific identification criteria** — states like Georgia have defined "affected infant" since CAPTA leaves interpretation of "affected by" to states, which creates real variation in who gets a POSC at all. In Georgia, if any one of the following criteria are met, an infant is considered “affected by prenatal substance exposure”
 1. **Infant Withdrawal or Harm:** The infant is experiencing symptoms of withdrawal, or exhibiting harmful effects in his/her physical appearance or functioning due to exposure to substances (legal or illegal).
 2. **Positive Infant Drug Screen:** The infant has tested positive for the presence of a substance or a metabolite thereof in his/her body, blood, urine, or meconium.
 3. **FASD Symptoms:** The infant displays symptoms of a Fetal Alcohol Spectrum Disorder (FASD).
 4. **Positive Mother Drug Screen (Illegal):** The mother tests positive for illegal substances at the birth of the infant.
 5. **Positive Mother Drug Screen (Prescription Misuse):** The mother tests positive for prescription drugs due to misuse at the birth of the infant.
 6. **Maternal Self-Disclosure:** The mother self-discloses substance use at the birth of the infant.

What does this mean for YOUR state?

Questions to Consider

Consider what CAPTA-related funding your state actually directs toward focused FASD efforts

Identification: How does your state identify infants and children affected by prenatal alcohol exposure/FASD, particularly as there is no toxicology test or withdrawal at birth?

Services: Once you identify infants and children that have PAE, what specifically happens next—and can you demonstrate that the child and family actually received services?

Accountability: Which state agency is ultimately responsible for ensuring that children affected by FASD do not disappear between child welfare, health, behavioral health, early intervention, and education systems?

Select PAE and FASD Resources



Use this QR code to access PAE and FASD Resources which includes publications, presentations, tools for parenting suggestions, reports, and recent materials to help professionals best serve families.

Discussion & Questions

Erin Ingoldsby, Ph.D.

(703) 247-2647

Ingoldsby@jbassoc.com

D. Crystal Coles-Quander, Ph.D., LCSW

(703) 483-8939

coles@jbassoc.com





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Slido #2158831

Sharing Out

We want to hear from you about today's discussions!

- What were some themes in your discussions?
- What was a major takeaway?
- What are concrete next steps for us to consider?

