Act Early Forum Webinar Series

Benchmarks for Monitoring Early Identification and Linkage to Services

May 9, 2013

Jointly sponsored by the Association of University Centers on Disabilities, the National Center on Birth Defects and Developmental Disabilities/Centers for Disease Control and Prevention, and the Maternal and Child Health Bureau/Health Resources and Services Administration
Webinar Overview

• Webinar Recording
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• Q & A
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• Survey
  - Please complete the short survey at the end of the webinar!
Introductions

**Catherine Rice**, PhD, Epidemiologist, Developmental Psychologist, National Center on Birth Defects and Developmental Disabilities/Centers for Disease Control and Prevention
Introductions

Elizabeth Twombly, MS, Senior Research Assistant, Instructor, Early Intervention Program, University of Oregon

Jane Squires, PhD, Director, Center on Human Development; Professor, Early Intervention/Special Education, University of Oregon

Jane Charles, MD, Developmental Pediatrician, Medical University of South Carolina
Project BEST: Benchmarks for Early Screening and Testing

Jane Squires, PhD, Principal Investigator
Liz Twombly, M.Ed., Project Coordinator

University of Oregon
Early Intervention Program
Project BEST

Develop precise, comprehensive benchmarks and recommended practices that can be used to evaluate the timeliness and efficiency of Part C early intervention programs in terms of conducting screening, evaluation, and entry into services.
Project BEST

Funded by: AUCD, Centers for Disease Control  RTOI #449

Principal Investigators

- Jane Squires, PhD
  - Director, Early Intervention Program & United Center for Excellence in Disabilities; University of Oregon

- Deb Eisert, PhD
  - Psychologist Child Development and Rehabilitation Clinic, Oregon Health Sciences University

Project Coordinator

- Liz Twombly, Senior Research Assistant
Project BEST Aims

- Improve timelines for screening and referral
- Improve early identification and access to EI/ECSE, especially for underserved populations.
Need
Need

- Timely intervention services are critical for optimizing developmental, health, and behavioral outcomes for young children.

- Project BEST will address one critical barrier—timeliness of screening and evaluation processes—resulting in improved outcomes for young children with developmental delays.
BEST Project Phases
Phase 1. Environmental Scan.

- An environmental scan was conducted on selected state data systems, available literature, and expert report on effective practices for measuring the number of children and early identification, screening and evaluation of infants and toddlers eligible for Part C early intervention services.

- Utilized a formative, mixed-methods approach
- Conducted an on-line survey
- Conducted local/state focus groups
  - Local/State Part C providers, health care providers
- Conducted a national focus group
  - November 30th, 2011; Center for Disease Control, Atlanta
  - Association of University Centers for Disability (AUCD)
  - Included stakeholders from federal and state agencies as well as parents of children with disabilities.
Project BEST Benchmarks & Recommended Practices
Benchmark #1. Universal Referral of Newborns and Children Automatically Eligible for Part C Services.

- All newborns and children with a diagnosed physical or mental condition that has a high probability of resulting in developmental delay, as defined by their state’s eligibility categories under Part C of IDEA, will be referred to their local Part C provider.
Benchmark 1: Examples of Process Indicators

• P 1.1 Linkage to Early Intervention.
  • Identification of linkage systems with birthing facilities, Neonatal Intensive Care Units (NICU’s), state birth defect registries, newborn screening programs…..

• P 1.2 Education and training.
  • Implementation of a training plan on state definitions of “Established Condition” eligibility category under IDEA

• P 1.3 Presumptive eligibility.
  • Use of expedited evaluation and enrollment procedures
Use of Presumptive Eligibility for Enrolling Children in Part C Early Intervention

Donald W. Mott & Carl J. Dunst (2006)

- Studied 180 children enrolled in Part C in NC
- Presumptive eligibility (PE) defined as:
  - “the process of determining a child's eligibility for IDEA Part C early intervention based on information about the child and family available at the time of referral”
- PE used for only 18% of the children
- PE could have been used for an additional 66% of the children
Benchmark #1.  
BEST Website Resource Examples

Colorado’s Database of Established Conditions
- Panel of physicians maintains database of conditions.

BEST Spreadsheet of Established Conditions
- Summarizes state definitions of identified conditions that have a high probability of delay.
- Newborn Screening Program conditions also identified.
Benchmark #2. Universal Screening and Referral.

- Children between the ages of birth and five are screened at least once every 12 months, with valid and reliable screening tool(s) that screen for developmental and social-emotional delays. If a concern is identified, procedures are in place to ensure appropriate and timely referral to Part C, Part B or other community support agencies as indicated by screening results.
Benchmark #2. Process indicators

- Statewide coordination of screening efforts
- Statewide public referral options
- Universal referral
- Education and training
- Screening by Primary health care and medical homes
  - BEST website “Check Your Knowledge”
• True or False. Periodic developmental and behavioral screening has been proven to enhance a primary health care provider’s ability to detect children who may develop developmental or behavioral problems over time.

• True. The American Academy of Pediatrics recommends screening all young children at 9, 18, and 24 (or 30) months, and screening for autism at 18 and 24 months. Numerous studies .........
Benchmark #3. Effective Identification of Underserved populations.

- All children, regardless of race or risk factors (e.g., low-income, homelessness), will have equal opportunities to participate in Part C Early Intervention services. State Part C agencies develop policies and procedures that support on-going and effective collaborative relationships with community agencies that serve underserved and at-risk populations.
Are Minority Children Disproportionately Represented in EI/ECSE?

Paul L. Morgan1, George Farkas, Marianne M. Hillemeier1, and Steve Maczuga (2013)

- Sample of 48-month-olds (N = 7,950)
- Early Childhood Longitudinal Study–Birth Cohort (ECLS-B),
- Increased likelihood of representation
  - very low birth weight
  - congenital anomalies
  - children engaging in externalizing problem behaviors
- Decreased likelihood
  - low- socioeconomic-status households
  - children with greater numeracy/receptive language knowledge
  - households where a language other than English is spoken
  - Black & Asian
Benchmark #3
Underserved Population
Process Indicators

- P 3.1 Underserved population planning
  - Creation of local annual plans to reach out to underserved.

- P 3.2 Targeted materials
  - Linguistically and culturally appropriate information available

- P 3.3 Community health workers / cultural brokers
Recommended Practice #1. Effective and Timely Part C Procedures.

State Part C agencies develop policies and procedures that support on-going and effective collaborative relationships with referral agencies as well as timely response to referrals and timely provision of services to infants and toddlers.
Effective and Timely Part C Procedures.
Examples of recommended practices

- **Education and training**
  - implement proven methods for increasing referrals from primary referral sources.

- **Part C verification of referrals**

- **Communication of referral results**

- **Definition of “referral.”**

- **Personnel preparation support**
Recommended Practice #2. Statewide Infant and Toddler Data System.

States have in place a web-based data system that tracks a child in the Part C system from referral entry throughout service delivery and transition. This data system provides features to improve timeliness of identification of children eligible for Part services, and data to measure timeliness and quality improvement outcomes of the Part C agency.
Recommended features of data systems

• **Features (Part C)**
  - Identifying underserved populations
  - Privacy protection and security practices and policies
  - Web-based public referral option
  - Part C referrals

• **Features (across key data systems)**
  - Unique statewide child identifier
  - Ability to link child-level data with other key data systems
  - Monitoring developmental status of at-risk children
The Status of Part C Data Systems
(Infant and Toddler Coordinators’ Association, 2013)

- 43 states indicated they are using a state-level centralized data system
  - 34 states indicated the data system is web-based
- 28 states indicated that their data system generates electronic notifications/reminders to service providers
- 39 states have unique identifiers for enrolled children
  - 21 states indicated that Part B uses a new identifier
  - 10 states responded that Part C identifier is also used in Part B
    (6 states archives the old identifier)
Recommended Practice #3
BEST Program Evaluation

- States have a method to evaluate progress towards the Benchmarks for Early Screening and Testing (BEST) program
Recommended Practice #3  
BEST Program Evaluation

• **Parent satisfaction**
  1) initial awareness and understanding of Part C services  
  2) ease of the referral process  
  3) timeliness of Part C response to referrals and  
  4) timeliness of service delivery to eligible children.

• **Primary referral source satisfaction**
  1) awareness and understanding of Part C services and the referral process  
  2) timeliness of Part C response to referrals, and  
  3) communication of referral outcome (e.g., changes in child status, eligibility evaluation results, services provided).
Summary
Benchmark #1: Universal Referral of Newborns and Children Automatically Eligible for Part C Services.

Benchmark #1: Universal Referral of Newborns and Children Automatically Eligible for Part C Services. All newborns and children with a diagnosed physical or mental condition that has a high probability of resulting in developmental delay, as defined by their state's eligibility categories under Part C of IDEA, will be referred to their local Part C provider.
Summary

- Project BEST aim was to develop benchmark and recommended practices related to timely identification, screening, evaluation and services.

- BEST Benchmarks and Recommended Practices are available at the BEST website.
  - [http://pages.uoregon.edu/projectbest/](http://pages.uoregon.edu/projectbest/)

- Overall goal is improving timeliness and access to Part C services, especially for underserved populations.
STAT-MD TRAINING
EARLY ID OF ASDs FOR PEDIATRIC PROVIDERS

THE DREAM, THE REALITY, A WORK IN PROGRESS

JANE M. CHARLES, MD
PROFESSOR OF PEDIATRICS
MEDICAL UNIVERSITY OF SOUTH CAROLINA
• Early intensive behavioral services = better prognosis. However, nationally, wait lists for dx evals are long.

• Diagnosis happens just before or after Part C services have ended, thus missing out on intensive therapy.
South Carolina ADDM: current age of first concern is less than 3 years old, BUT average age dx is 4 years 6 months (ADDM 2009)
Importance of Effective Early ID of ASD

- CDC determines ASD as a health issue of “critical importance”. (CDC 2009)

- Early ID provides more intervention opportunities.

- More intervention = can optimize long term outcome, reduce lifetime cost of services, improve functional independence
American Academy of Pediatrics Recommendations

- **Autism Toolkit 2007**
  - Algorithms for ASD and gen’l developmental screening
  - Surveillance and screening tools for different age groups
  - Fact sheets for MDs re: management of specific issues-sleep, GI, behaviors, eating/nutrition.
  - Family information handouts

- **MCHAT: Screen at 18 and 24 mo.**
  - More frequent in high risk kids or delayed
  - Screen x 2 to catch regression
  - Free off Internet
  - Positive screens followed by immediate referral for an evaluation and then, initiation of intensive services
However.....

- **Long waits** for gold standard multi-disciplinary evaluations: 6-12 months
- **Delay** in initiating intensive therapies
- **IDEALLY**: + screen → rapid initiation of intensive services regardless of diagnostic status.
- Then: later confirm with gold std evaluation.
GOLD STANDARD DX EVALUATION

- Autism Dx Observation Schedule + Autism Dx Interview-Revised (comprehensive interview tool)
- Developmental Assessment-Lang/cognitive/ADLs
- Medical Eval- Hx, physical, growth, dysmorphology exam, vision, hearing.
- Further studies if hx suggests: EEG, MRI, etc.
Can ASDs be accurately dx'd in first years of life
When is Diagnosis possible?

- **Landa and Mayer (2006)**
  No statistically significant group differences detected at 6 months
  By 14 months the ASD group significantly worse on all scales (Mullen scales)

Conclusion

  Unusual slowing occurred between 14-24 months
When is Diagnosis possible

- **Zwaigenbaum et al (2009)**
  - To date, prospective studies have shown that by 12 to 18 months of age, infants later diagnosed with ASDs are distinguished from other infants at high risk.

- **Ozonoff et al (2010)**
  - Group differences were significant by 12 mo of age on most variables.
“The Challenge”
Zach Warren, PhD

- Create a framework for performing ASD diagnostic evaluation within community-based practices that can:
  - **Reduce waits** between screening concerns and diagnostic/service delivery
  - **Meet time demands**
  - **Accurately identify** both kids with and without ASDs
  - **Link children** with appropriate early intervention services.
  - **Be adequately reimbursed!**
TENNESSEE AAP: ‘START-ED’

- Vanderbilt University+Tenn AAP:
  - Wendy Stone, PhD and Zach Warren, PhD.
  - Vanderbilt Kennedy Center Treatment and Research Institute for Autism Spectrum Disorders

- Trained groups of interested ped providers to become regional STAT consultants to screen M-CHAT positive kids.

- Part C program agreed to accept results of second level screener to start early intensive services while waiting for confirmatory “gold standard” dx eval.
SCREENING TOOL FOR AUTISM IN TODDLERS

- For referral populations
- 12 item play-based tool to assess key social and communicative behaviors: Play, communication, joint attention, motor imitation
- 20 min to administer
- 24-36 mo (can use from 18-36+)
- Sensitivity: 0.92
- Specificity: 0.85
South Carolina STAT MD Training

- **Regional Act Early Summit Meeting**, Nashville, TN 2008. USC UCEDD + key stakeholders, agencies, service providers, parents

- **Act Early State Plan**: two projects
  1. Road Map
  2. STAT-MD

Funded by grant from Association of Maternal and Child Health (AMCHP). “Act Early State Systems Grant”
1 ½ days intensive training
- Core features of ASD
- STAT training
- Diagnostic interviewing and templates
- Discussing results with parents
- Billing and Coding
- Service recommendations, referrals, managing co-morbidities
- +CME
- Pediatricians, Family Med, Nurse Practitioner, nurse manager of large practice, State agency consultants, MUSC devel peds faculty
1. Medical assessment
   - r/o sensory deficits
   - Neurodevelopmental hx
   - Physical exam

2. Semi-structured social interaction
   - STAT
   - Observations in waiting room and free play
   - Structured clinical interview
     - Specific developmental hx probes
CODING

- Details in AAP Toolkit
- 96110- Screening
  - M-CHAT at 18 and 24 mo
  - Pays for clinical staff time, supplies, insurance liability

- 96111-Developmental Testing
  - STAT
  - Includes assessment of motor, language, social adaptive &/or cognitive functioning by standard developmental tools.
  - MD or “other trained professional” can administer.
  - RVUs for MDs
IMPLEMENTATION

1. One year process to change Part C policy
2. Part C staff was trained in new policy, so actual STAT evals did not become available until October 2012.
3. Dept of Disabilities and Special Needs (DDSN) had concerns about reliability and experience of STAT providers, ie the MDs providing the screening.
4. DDSN – must apply to be on list of reliable providers:
   1. 4 Developmental Pediatricians
   2. 4 primary care peds
   3. 4 PHD psychologists
   4. 1 LPN, 1 MSW, 1 BSW
   5. 11 Autism Consultants from DDSN
IMPLEMENTAION

- Two trainings so far– lower state and upper state.
- Future trainings will be funded by DDSN
- Concern with MD use and lack of experience administering standardized tools.
  - Plan to add extra training on standardized testing for MDs for those MDS interested.
  - Commitment to doing a specified number of STATs
  - Commitment to regular “re-training” for reliability.
  - This will reduce the number of primary care peds in network of STAT-MD providers.
  - However, assures integrity of program
Since October 2012

STATs Completed by the Autism Division

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Barriers and Future Considerations

- Still seems to be some confusion with EIs knowing to making referrals for STATs for presumed eligibility.
- Having ongoing source of funding for training providers
- Extra training for MDs re: using standardized tools.
- Arranging provider follow up to maintain reliability.
- Some issue with PCPs charging for developmental testing, need to investigate this.
Q & A

• Ask a question!
  - Type your question in the “question box” on your webinar dashboard.
  - The moderator will read the question.
Thank You!

• Learn more about Act Early!
  - www.cdc.gov/actearly
  - www.aucd.org/actearly

• Questions about the webinar?
  - Email Tory Christensen (tchristensen@aucd.org)

Please take a few minutes to complete the survey!