Developmental Screening and Surveillance

New Recommendations for Children in Louisiana

Susan Berry, MD, MPH, FAAP
Professor of Clinical Pediatrics, LSUHSC
Medical Director, CYSHCN Programs, BFH
Disclosure

I have no relevant financial relationships with commercial interest to disclose.
Outline

1. Why screen? The importance of early intervention
2. Current and evolving recommendations for expanded developmental surveillance and screening
3. Screening and surveillance in LA: What does the data show?
4. Recommended tools for expanded developmental screening for LA children
The Abecedarian Project (1972-1985)
Frances Campbell, Craig Ramey, et al

- 111 infants; randomized control and intervention groups, followed from birth to five years
  - **Controls**: social support, nutrition supplements
  - **Intervention**: same as controls, plus enriched daycare with emphasis on language development, warm relationships

- Followed for 30 years
Outcomes of the Abecedarian Project

- **At age 15:** Higher IQ scores, lower grade retention, less need for special education

- **At age 21:** more likely to attend a 4 year college, be in school or have a skilled job, less likely to become a teen parent, report depression, or smoke marijuana

- **At age 30:** more likely to have a bachelor’s degree (23% vs 6%), hold a job (74% vs 52%), or delay parenthood (average of 2 years)

- **In 2014:** improved physical health, lower obesity and hypertension, **none** had metabolic syndrome (vs 1 in 4 in the control group), lower risk of coronary heart disease, stroke, and diabetes (Heckman, Science 2014)
Benefits of Early Intervention

Children who participate in early intervention programs are more likely to:

- Finish high school
- Hold jobs
- Live independently
- Avoid teen pregnancy, delinquency and crime
The ACES Study (1995-1997)

- 17,337 Kaiser Permanente HMO members, average age 57
  - 75.2% had attended college
  - All had good jobs and good health care

- Asked about 10 types of childhood trauma:
  - Physical abuse
  - Sexual abuse
  - Emotional abuse
  - Physical neglect
  - Witnessed maternal violence
  - Household substance abuse
  - Household mental illness
  - Incarcerated household member
The ACES Study: Outcomes

- ACES are common:
  - >60% had at least 1 ACE; 40% had 2 or more ACES; 12.5% had 4 or more ACES
  - 28% reported physical abuse; 21% sexual abuse

- # ACES was positively correlated with high risk health behaviors, including: smoking, alcohol, drug use, promiscuity, and severe obesity

- # ACES was positively correlated with depression, heart disease, cancer, chronic lung disease, and shortened lifespan

- Having 4 ACES vs 0 ACES was associated with a 7x increase in alcoholism, 2x risk of cancer, 4x increase in emphysema
The Role of Experience in the Developing brain

- Neuronal networks develop in response to the environment through epigenetic mechanisms.
- Environmental stimulation is essential for normal development.
- ACES inhibit neurogenesis and alter early brain architecture and the biochemistry of neuroendocrine systems.
- Chronic stress disrupts the regulation of stress hormones including cortisol, norepinephrine, and adrenaline.
700 New Neural Connections Every Second

Image adapted from Courchesne et al., 2007
Screening and surveillance

12-18% of children have a developmental or behavioral problem; the question is which 12-18%?
Common Disabilities in Children

- ADHD
- autism spectrum disorders
- speech and language disorders
- cerebral palsy and other motor disabilities
- intellectual disabilities
- learning disorders
- vision/ hearing loss
Prevalence is increasing!

<table>
<thead>
<tr>
<th>Disability</th>
<th>1997-1999, %</th>
<th>2006-2008, %</th>
<th>Percent Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any developmental disability</td>
<td>12.84</td>
<td>15.04</td>
<td>17.10</td>
</tr>
<tr>
<td>ADHD</td>
<td>5.69</td>
<td>7.57</td>
<td>33.00</td>
</tr>
<tr>
<td>Autism</td>
<td>0.19</td>
<td>0.74</td>
<td>289.50</td>
</tr>
<tr>
<td>Learning Disability</td>
<td>6.86</td>
<td>7.24</td>
<td>5.50</td>
</tr>
<tr>
<td>Other Developmental Delay</td>
<td>3.40</td>
<td>4.24</td>
<td>24.70</td>
</tr>
</tbody>
</table>

Boyle, et al., 2011; Centers for Disease Control, 2013
Increasing prevalence of emotional/behavioral disorders

- Developmental and behavioral disorders are the top 5 chronic pediatric conditions causing functional impairment (outpacing physical conditions!)

- 37-39% of children will have a behavioral or emotional disorder by age 16;
  - Impulse control/behavioral problems
  - Anxiety
  - Mood disorders

- Studies demonstrate that pediatricians only detect about 14%-50% of behavioral/emotional problems; only about 50% use a standardized screening tool

- Only 1 in 8 children with a mental health problem receive treatment

Developmental Surveillance (AAP 2006; reaffirmed Aug 2014):

the process of recognizing children who may be at risk for developmental delays by:

1. elicit parent concerns
2. maintain a developmental history
3. make accurate observations
4. identify risk and protective factors
5. document the process and findings in the medical record
Eliciting parent concerns:

- Only 30-40% of parents will volunteer a concern without prompting
- ASK parents if they have any concerns about their child’s *development or behavior*
- Never ignore a parent’s concerns
Developmental Surveillance:

Maintaining a developmental history:

- “What is new in your child’s development since his last visit?”
  - delays
  - regression
  - dissociation
  - deviance
Developmental Surveillance: Observations

- Parent child interactions
- Provider interactions: does the child look at you? Is his speech age appropriate? Does the child point to show you things?
- Delays noted during the physical exam
Developmental Surveillance

Identify risk and protective factors (environmental, genetic, biologic, social and demographic)

**Protective factors:**

Warm, nurturing family  
Stable marital relationship  
Stable source of income  
Parent education  
Social support network
Developmental Surveillance: Medical Risk Factors

Prenatal:

- Lack of prenatal care
- Genetic conditions
- Congenital infections (toxoplasmosis, CMV, herpes, HIV, varicella, syphilis)
- Teratogen exposure (drugs, alcohol, lead)
- Maternal illness (fever, infections)
- Nutritional deficiencies
- Vascular events, hypoxia
- In vitro fertilization
- Multiple births
Developmental Surveillance: Medical Risk Factors

Perinatal:

- neonatal asphyxia
- intra-ventricular hemorrhage
- central nervous system infection
- hyperbilirubinemia
- neonatal seizures
- prematurity
- bronchopulmonary dysplasia
Developmental Surveillance: Medical Risk Factors

Postnatal:
- accidents (car, child abuse, near drowning, poisonings, aspiration)
- CNS infections (meningitis, encephalitis)
- lead toxicity
- brain surgery
- psychosocial vulnerability → *Adverse Childhood Experiences (ACES)*
Risk Factors for Toxic Stress/Adverse Childhood Experiences

- Maternal depression or mental illness
- Parental substance abuse
- Domestic or community violence
- Food scarcity
- Poor social connectedness
- Parent incarceration
- Sexual or physical abuse
Developmental Screening:

the use of standardized tools to identify children who are at a high probability of having a developmental delay and who are in need of further evaluation.

AAP Policy Recommendation:

- screen for delays at 9, 18 and 30 months
- screen for autism at 18 and 24 months
- when there is physician or parent concern
Increased risk identified through surveillance should prompt increased frequency of screening!

- Physicians are not very good at recognizing delays in a timely manner.
- Parents are not very good at volunteering their concerns if not prompted.
Bright Futures Periodicity Schedule
Committee on Practice and Ambulatory Medicine, Bright Futures Periodicity Schedule Workgroup

- Updated annually:

- Only change in developmental or autism screening since 2006 Policy is the 24-30 month developmental screening is now 30 month screening

- **February 2017 Update**: psychosocial/behavioral assessments at every visit
  “Psychosocial/behavioral assessment should be family centered and may include an assessment of child social emotional health, caregiver depression, and social determinants of health”

- **Louisiana EPSDT Guidelines**: last updated October 2013; agrees with current Bright Futures periodicity schedule
A note on parent questionnaires...

Validated Parent Questionnaires are:

- Reliable
- Family-centered
- Take less time
- Do not require the child’s cooperation
- Do not require certification
- Can be completed in the waiting room
- Can be handled by front desk
- Quick to score
- Cost-effective
Screening Tests...

- Do not tell you diagnosis
- Do not tell you developmental level
- Do not tell you prognosis

*Do help determine which children need assessment, what areas are of concern, and what types of professionals should be involved*
Challenges in Office-based Screening:
lessons from national demonstration projects

- Consistent referral of children with failed screens
- Distributing screens to children at screening age but not to others
- Not screening when surveillance raises concerns
- Maintaining screening procedures during busy office times
- Coping with screening gaps due to staff turnover
- Tracking referrals
- Non-adherence to the 30-mo screen because of expected non-reimbursement (not a problem with LA Medicaid)

Federal Law

Individuals with Disabilities Education Act (IDEA) Amendments of 1997, 2004

Healthcare providers must refer a child to early intervention or the school system as soon as possible but no more than 7 days after identification.
Promoting Developmental Screening: lessons from national demonstration projects

- Creating an office-wide implementation system
- Dividing responsibility among staff
- Actively monitoring implementation and continuing to make changes
- Choosing screens that least disrupt clinic flow
- Aligning screening measures with those used in community based programs
## Status of developmental problems in LA children
**NSCH 2012**

<table>
<thead>
<tr>
<th>Child and Family Measures</th>
<th>Louisiana</th>
<th>US</th>
</tr>
</thead>
<tbody>
<tr>
<td>% children 4 mo to 5 years at moderate to high risk of developmental problems</td>
<td>30.3%</td>
<td>26.2%</td>
</tr>
<tr>
<td>% CYSHCN</td>
<td>22.9%</td>
<td>19.8%</td>
</tr>
<tr>
<td>% with 2 or more ACES</td>
<td>26.0%</td>
<td>22.6%</td>
</tr>
<tr>
<td>% children 10 mo to 5 years who received a developmental or behavioral screening</td>
<td>37.3%</td>
<td>30.8%</td>
</tr>
<tr>
<td>% children who receive care within a medical home</td>
<td>55.7%</td>
<td>54.4%</td>
</tr>
<tr>
<td>% who needed mental health counselling and received it</td>
<td>40.4%</td>
<td>61.0%</td>
</tr>
</tbody>
</table>
2015 LA Title V CYSHCN Needs Assessment

National Survey Results

Family Focus Groups

Physician Survey
N=1338; n=191
"I thought I was a good advocate for him, but they kept saying it was first-time mommy, first-time mommy. And this is the pediatrician constantly telling me there was nothing wrong with him."
-Mother of a child with autism

Developmental Screening

Physicians’ Use of Developmental Screening Tools

- Correct Use: 6%
- Use: 85%
## Developmental Screening Tools Used by LA pediatricians and family practitioners (2015)

<table>
<thead>
<tr>
<th>Tool</th>
<th>% Use</th>
<th>% Use Correctly</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASQ</td>
<td>54%</td>
<td>9%</td>
</tr>
<tr>
<td>Child Development Chart/ CDI</td>
<td>48%</td>
<td>6%</td>
</tr>
<tr>
<td>PEDS/PEDS DM</td>
<td>28%</td>
<td>3%</td>
</tr>
<tr>
<td>Denver II</td>
<td>53%</td>
<td></td>
</tr>
<tr>
<td>R-PDQ</td>
<td>15%</td>
<td></td>
</tr>
</tbody>
</table>

Others listed include: EHR tool, parent interview with Bright Futures questions
Autism Screening

Percent of Physicians Reporting Use and Correct Use of the MCHAT Among All Physicians

- Uses Correctly*
- Uses Incorrectly

<table>
<thead>
<tr>
<th>Family Practitioners</th>
<th>Pediatrics</th>
<th>All Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>27%</td>
<td>20%</td>
<td>46%</td>
</tr>
<tr>
<td>1%</td>
<td>9%</td>
<td></td>
</tr>
</tbody>
</table>

*Correct use = at ages 18 and 24-30 mo and when parent or physician is concerned
Why aren’t providers screening?

- Inadequate visit time: 80%
- Inadequate Reimbursement: 56%
- Lack of nonphysician staff: 50%
- Not familiar with CPT codes: 47%
- Few community resources: 33%
- Inadequate training in developmental services: 28%
- Lack of familiarity with instruments / tools: 24%
How do you pick a developmental screening tool?

- Sensitivity and specificity at least 70% to 80%
- Validated with a population similar to the population being screened (SES, culture, language, and literacy level)
- Published in a peer-reviewed journal
- Quick, easy to use, low cost
- For general development, screens gross motor, fine motor, language, cognition and personal-social domains
Screening for Mental Health Concerns:

A Clinician’s Toolkit: “Mental Health Screening and Assessment Tools for Primary Care”, 2010 Revised 2012


Pediatrics Vol 135, no 2 February 2015
Young Child Wellness Collaborative
Developmental Screening Workgroup

Mary Margaret Gleason, MD, FAAP- Tulane Child Psychiatrist
Susan Berry, MD, MPH, FAAP- LSU Developmental Behavioral Pediatrician,
   Title V CYSHCN Medical Director
Brenda Sharp, MA, CCC-SLP- Early Steps
Gina Easterly, CCC-SLP- BFH Maternal, Infant, Early Childhood Home
   Visiting (MIECHV) Program
Ana Bales- BFH Infant Mental Health
Kristin Savicki, PhD – Child Psychologist, LDH OBH and ADHD Taskforce
Jessica Diedling, MPH – BFH MIECHV Program Analyst
Patti Barovechio, DNP MN – OPH CSHS Statewide Care Coordinator Supervisor
Expanded Developmental Screening and Surveillance

- Developmental
- Autism
- Social-emotional
- Environmental (risk of maltreatment or abuse)
- Parent Depression
# Recommended Screening Tools for Louisiana

**Early Childhood Wellness Collaborative Developmental Screening Workgroup**

<table>
<thead>
<tr>
<th>Domain(s)</th>
<th>Tools Selected</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Development</td>
<td>ASQ-3</td>
<td>Use with AAP schedule (9, 18, 30 months)</td>
</tr>
<tr>
<td>Autism</td>
<td>mCHAT</td>
<td>Use with AAP schedule (18, 24 months); valid from 16 to 30 mo</td>
</tr>
<tr>
<td>Social Emotional</td>
<td>ECSA, PPSC, ASQ-SE</td>
<td>per LA collaborative</td>
</tr>
<tr>
<td>Environmental</td>
<td>SEEK</td>
<td>per LA collaborative</td>
</tr>
<tr>
<td>Parent Well-being</td>
<td>PHQ2 (part of SEEK, or stand alone)</td>
<td>2 question screen for maternal depression</td>
</tr>
</tbody>
</table>
Recommendations of the Louisiana Early Childhood Wellness Collaborative Developmental Screening Workgroup

<table>
<thead>
<tr>
<th>Age (months)</th>
<th>0</th>
<th>2</th>
<th>4</th>
<th>6</th>
<th>9</th>
<th>12</th>
<th>15</th>
<th>18</th>
<th>24</th>
<th>30*</th>
<th>36</th>
<th>48</th>
<th>60</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gen Dev</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Autism</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Social Emotional</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Environmental</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Parent Well-being</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

*30-month visit is recommended by AAP and added to the EPSDT screening schedule

(-) Denotes that screening should occur once during the range of visits in parentheses
Ages and Stages Questionnaire - 3rd edition

- Age range 1 to 66 months
- 21 questionnaires for different ages; 30 questions each rated “yes”, “sometimes”, or “not yet”
- Reading level 4th to 5th grade
- Takes 10-15 minutes for parent to complete; 2-3 minutes to score
- Screens communication, gross motor, fine motor, problem solving and personal-social
- Sensitivity 86%; specificity 85%
- $275 for starter kit; can freely Xerox within the practice
modified-Checklist for Autism in Toddlers (m-CHAT)

- For children ages 16 to 30 months
- Takes parent 5-10 minutes to complete
- 20 questions; “no” indicates no risk except for 3 questions with reverse answers, where “yes” indicates no risk
  - Score of 0-2 = low risk
  - Score of 3-7 = medium risk
  - Score of 8-20 = high risk
- Public domain (https://www.m-chat.org/mchat.php)
- Sensitivity 85%; specificity 91%; specificity is improved with m-CHAT follow-up questionnaire
Ages and Stages Questionnaire: Social Emotional (ASQ-SE-2 2015)

- **Age range:** 1 mo-6 years, 9 different forms with approx. 30 questions each; 4th to 8th grade reading level

- **Time required:** 10-15 minutes

- **Sensitivity:** 78% at 2 mo; 84% at 24 mo; **specificity** 76% at 18 mo; 98% at 60 mo; compared with CBCL and SEEK

- **Cost:** $275 for starter kit; forms can be copied

- **Developmental Domains Screened:**
  - Self-regulation
  - Compliance
  - Communication
  - Adaptive Functioning
  - Autonomy
  - Affect
  - Interaction with people
Early Childhood Screening Assessment (ECSA)

- 18-60 mo
- 40 items; only one form
- time to complete: 5-10 minutes
- time to score: 1-2 minutes
- items rated 0, 1, or 2 for “not true”, “somewhat”, “very true”
- “plus sign” indicates concern and desire for help with that item
- score = sum of the circled items; ≥ 18 is positive
- 83% sensitivity and 86% specificity predicting psychiatric disorder by structured interview.
Preschool Pediatric Symptom Checklist

- Ages: 18-60 months
- Format: 18 items
- Domains: Social emotional (internalizing, externalizing, attention problems, parent challenges)
- Scoring: ≥9 considered positive
- Validation sample: diverse SES and race
- Validated vs. Child Behavior Checklist, ASQ:SE
  - 88% sensitivity, 89% specificity
- Cost: Free at theswyc.org
Safe Environment for Every Kid (SEEK) Parent Questionnaire - Dubowitz

- Identifies families at risk for maltreatment
- 15 yes-no questions
- Starts with low intensity risk factors and then includes food instability, parent stress, corporal punishment, interpersonal violence
- Includes screening for parent depression
- Implementation in primary care associated with reduced parent-reported psychological aggression and minor physical assaults, reduced child protection reports
Patient Health Questionnaire-2 (PHQ2) Whooley, et al

- 2 question screen for parent depression
  - During the past month, have you often felt down, depressed, or hopeless?
  - During the past month, have you often had little interest or pleasure in doing things?
- Sensitivity 83%-87%; specificity 78-92%
- Included in ECSA and the SEEK or can be used alone
One screener for everything?

Survey of Well-being of Young Children (SWYC):

- ages 2-60 months, 12 age-specific forms, 15 min to complete, free to download

Assesses:

- **Developmental milestones**: cognitive, language, motor
- **Autism** (Parent’s Observations of Social Interaction (POSI) for ages 16-35 months
- **Emotional/Behavioral**: Baby Pediatric Symptom Checklist (12 items; < 18 mo) and Preschool Pediatric Symptom Checklist (18 items; 18-66 mo)
- **Family Context** (9 items): assess stress including parent depression, discord, substance abuse, food insecurity, and parent concerns
- **Edinburgh Postnatal Depression Scale** for 2, 4, and 6 month forms

Psychometrics: high sensitivity, lower specificity; standardization ongoing
CPT Codes for Developmental Screening

- **96110**: developmental screening and autism screening (eg ASQ, mCHAT); use for each screen separately; does not include physician interpretation and management

- **96111**: extended screens (generally > 1 hour) with a direct testing component/developmental assessment (CARS, ADOS); includes interpretation and a formal report

- **96127**: brief emotional/behavioral assessment with scoring and documentation, per standardized instrument (eg depression inventory, ADHD screens, ECSA, ASQ-SE, BASC, PSC, SCARED)

- **99160**: patient-focused health risk assessment with scoring and documentation, per standardized instrument (eg CRAFT)

- **96161**: screen for health risks in the care giver that benefit the patient with scoring and documentation, per standardized instrument (formerly 99420) (eg SEEK, PHQ-2 for maternal depression)

*Effective January 1, 2017*
Who should screen?

- **Physicians** should provide surveillance and screening in a medical home that provides comprehensive coordinated care

- **EarlySteps and Child Search** provide screening to determine areas in need of assessment

- **DCFS** can screen children in foster care to help determine need for mental health/early intervention services

- **Home visiting programs** can screen at risk mothers and young children

- **Child care workers and early interventionists**
Sources of Comprehensive Assessment

- EarlySteps (0-3 years)
- School System (Child Search)
- Psychologists
- Developmental Pediatricians
- OT, PT, speech therapists, early interventionists
Comprehensive Developmental Assessment Goals

- To delineate the child’s abilities and compare them to the typical child
- To determine eligibility for services
- To provide information for program planning
Are Children in Louisiana Getting the Early Intervention they need?

In 2012-2013 2.13% of Louisiana children age 0-3 received early intervention services versus 2.77% nationally (LA IDEA report)
Management:
The Role of the Medical Home

- Schedule early return visits for children at risk with normal screens

- Begin *chronic condition management* for any child identified with a developmental delay:
  - Enter the child into the practice registry of CYSHCN
  - Conduct a comprehensive family needs assessment and develop a written care plan
  - Review the developmental assessment and intervention plan and advocate as needed
  - Identify associated medical problems and initiate work up
  - Link with community and public health services (FHF, OCDD, Medicaid, SSI)
Title V Resources for Practices

- Webinars offer free CME for nurses and social workers:
  - [http://www.hdc.lsuhs.edu/Modules/webinars.php](http://www.hdc.lsuhs.edu/Modules/webinars.php)
  - Medical home
  - Care coordination
  - Transition to adulthood
  - Early intervention
  - Developmental screening
  - Family-centered care
  - Navigating the school system

- Title V offers free trainings in developmental screening and care coordination including continually updated resources for easy referrals
For further reading...


http://www.developingchild.net
Thanks!!