Developmental, Autism, Social-Emotional & Psychosocial Screening: Tools and Practices

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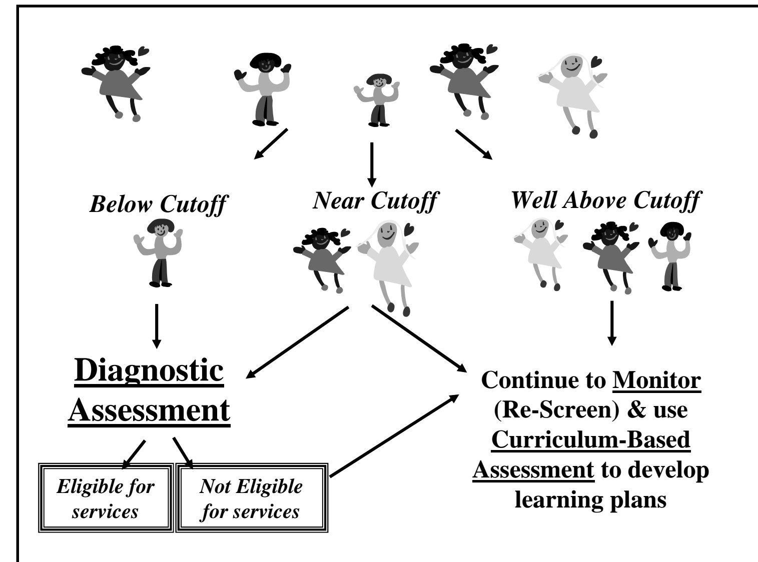
Original publications:
1. "Impact of Implementing Developmental Screening at 12 and 24 Months in a Pediatric Practice", *Pediatrics*, 8/2007
2. "The Thorny Nature of Predictive Validity Studies on Screening Tests for Developmental-Behavioral Problems ", *Pediatrics*, 10/2008
3. "Lowering Developmental Screening Thresholds and Raising Quality Improvement in Preterm Children", *Pediatrics*, currently in press



Why do Universal Screening & Surveillance?

1. Early Intervention improves developmental outcomes (especially with low SES/ Medicaid, mildly delayed and autistic children)
2. Improved outcomes = higher achievement in math & reading + less antisocial behaviors, suicidal thoughts/attempts,smoking, alcohol & THC use… at 18 years of life

   -McCormick et al, March Pediatrics, 2006
2. Yet, pediatricians fail to identify & refer 60 – 80% of of children with developmental delays in a timely manner

ECDP Cost/Benefit Analysis

For every $1 invested in a Early Childhood Development Program, the return rate in benefits

= $3.78 (Abecedarian study)

= $17.07 (Perry Preschool Study)

ECDP Cost/Benefit Analysis

- If every low-income 3-4 yr olds (20% of U.S. children) received 2 yrs of a quality ECDP, the investment yields a 16% annual return rate in cost savings to society and…
  - greater language abilities, better academic achievement (in math & reading), less remediation & special education in public schools, lower drop-out rates…
  - less alcohol use, less drug use, lower teenage pregnancy rates, less crime, less poverty, lower rates of abuse & neglect…
  - more educated workers, less welfare dependency, higher national gross domestic product, etc…

ECDP Cost/Benefit Analysis

"Future proposed economic development should have early childhood development at the top"

- A. Rolnick, R. Grunewald, Economic Analysts

ECDP Cost/Benefit Analysis

- Currently we spend $6 billion/ yr on ECDP
- If every 3-4 yr, low-income child in the U.S. were in a quality ECDP, that $19.4 billion/ yr investment would yield cost savings of…
- = $167 billion (for public education) + $422 billion (for crime) + 0.43% increase of GDP (for economy) + 0.25% of GDP (increased tax revenue for Social Security) for our government & society projected by 2050 – R Lynch, Economic Analyst

AAP Recommendations

- Based on evidence-based but mostly expert opinion..
- General dev. screening universally at 9, 18 and 30 (vs. 24) months + as needed if developmental and/or behavioral concerns arise
- No current AAP recommendations about social-emotional, family psychosocial or post-partum mood disorder screening
- Autism-specific screening universally at 18 and 24 months+ as needed if parent, clinician or other caregiver ASD concerns
- The AAP has not unified general developmental, autism-specific, social-emotional, psychosocial and post-partum mood disorder screening recommendations

When to Screen?

What would generate the largest # of appropriate referrals--
Universal screening at 6, 9 and/or 12 months?

- 6 months- good time to universally ask about vision and hearing
- 6 months- good time for gross motor delay identification
- 9 months- evidence says early signs of autism can be identifiable
- 3rd edition ASQ will have a 9 mo interval
- 12 months- anecdotally, kids present to their 12 mo visit soon after their 1st birthday, making paper-based screening easier
- 12 month ASQ- better psychometric properties than 8 or 10 mo ASQ
- 12 months- social communication problems/ ASD more apparent
- Best approach: screen at 9 months but if missed, 12 months **?**

When to Screen ?

What about screening > 30 months?

- Squires and Glascoe both strongly recommend it
- 2006 AAP statement: "At 4 years, screening for school readiness is appropriate."
- Oregon's special education eligibility requirements are less strict after 3 years of life
- 36 month ASQ is highly accurate and Headstart will preferentially enroll "at risk" children at 3 years (prioritize them on a waiting list) in Oregon

When to Screen?

Better to do universal screening at 24 vs. 30 months?

- 24 & 30 month ASQ- both have great psychometric properties
- No reimbursable 30 month well-child visit in Oregon
- Anecdotally, kids present to their 24 month visit soon after their 2nd birthday, making paper-based screening easier
- Autism Expert Panel/ Gupta recommends 24, not 30 months because identifying autism earlier is better than later

What Screening Tool to Use?

- 2006 AAP Developmental Surveillance and Screening Statement
- No formally recommend screening tool
- Pediatricians given their choice of 9 general, 3 language/ cognitive, 2 motor and/or 6 autism-specific screening tools.
- 20 options = extra homework for every pediatrician

-Some tools are less accurate

-General tools are logically better for primary screening

-Some tools are lengthy, not office feasible

-Parental questionnaire tools –more feasible than direct observable screening tools

What Screening Tool to Use?

- Commonwealth Fund Screening Recommendations from Drs Drotar Ph.D, Stancin Ph.D, and Dworkin, MD
- Is the primary purpose surveillance vs. screening?
- If surveillance only, then use PEDS
- PEDS is a screen
- Is this "real-world" advice for busy general pediatricians?
- Bright Futures Guidelines have targeted tasks/ objectives crammed into every well-child check but…
- Developmental surveillance at every visit is recommended

What Screening Tool to Use?

- Commonwealth Fund Screening Recommendations from Drs Drotar, Stancin and Dworkin
- Is the primary purpose surveillance vs. screening?
- If general screening, parent-report tool desired…
- Low-risk population? then use ASQ vs. PEDS
- High-risk population? then use ASQ

What Screening Tool to Use?

- If surveillance only, then use PEDS
- PEDS is actually more time-efficient, reliable and validated compared to unvalidated, unreliable Denver II milestone review checklists.
- PEDS-online seems more feasible than paper-based PEDS
- Feasible to implement PEDS for all non-ASQ screening visits?
- Maybe if there was an online-PEDS & ASQ tool?
- What about PEDS:DM for all non-ASQ well-child checks?

What Screening Tool to Use?

- Commonwealth Fund Screening Recommendations from Drs Drotar, Stancin and Dworkin
- Is the primary purpose surveillance vs. screening?
- If general screening, practitioner-based measure desired, high-risk population, then…

1. Bayley Infant Neurodevelopmental Screen (BINS)

   vs.

2. Cognitive Adaptive Test/ Clinical Linguistic Auditory Milestone Scale- Expressive and Receptive Language Scale (CAT/CLAMS)

What Screening Tool to Use?

- Commonwealth Fund Screening Recommendations from Drs Drotar, Stancin and Dworkin
- Is the primary purpose general vs. specific screening?
- Language screen, parent report measure desired…

  Language Developmental Survey (LDS)
- Language screen, practitioner-based measure desired..

  Clinical Linguistic Auditory Milestone Scale- Expressive and Receptive Language Scale (CLAMS)

What Screening Tool to Use?

- What's a low-risk population?
- Regular WCC, full term, good maternal prenatal care, normal birth weight, normal growth, adequate financial resources, healthy parents, 2 parent family….
- Is this a relatively high % of your patient population?
- Do you not have many Medicaid or uninsured patients in your pediatric practice?
- If yes, then use ASQ or PEDS

What Screening Tool to Use?

- Commonwealth Fund Screening Recommendations from Drs Drotar, Stancin and Dworkin
- Is the primary purpose general vs. specific screening?
- If autism-specific screening tool desired…
- M-CHAT is recommended
- A more detailed autism evaluation should be done by an autism evaluation team per the AAP's ASD identification algorithm guidelines

What Screening Tool to Use?

- What is an intermediate-risk population?
- Intermittent WCC or maternal prenatal care, prenatal tobacco exposure, feeding/ growth problems, multiple caregivers ("grandma helps out"), stressed parents, single-parent families…
- Is this a relatively high % of your patient population?
- Do you see uninsured patients (less frequent WCVs)?
- If yes, then use … ASQ > PEDS

What Screening Tool to Use?

- What is a high-risk population?
- Infrequent WCC, no maternal prenatal care, premature birth, prenatal drug or alcohol exposure, low birth weight, genetic disorder, chronic illness, feeding/ growth disorders, poverty, foster care, international adoption….
- Is this a relatively high % of your patient population?
- Do you care for Medicaid/ low SES patients?
- If yes, then use … ASQ

What new war would be a long-term solution to our troubled economy?

Oregon's ABCD Recommendations

- Oregon's ABCD steering committee's recommendations:
- "include but are not limited to: ASQ, ASQ:SE, PEDS +/- PEDS:DM, M-CHAT"
- ASQ, ASQ:SE and M-CHAT are best fit for Oregon
- ASQ and ASQ:SE were validated & normed on many Oregonians
- If a practice chooses PEDS, then consider PEDS:DM too!
- PEDS is a better fit for practices that feel strongly about "quality" screening at every WCV

America's New Charge!

Operation: "Early Intervention"

Parent-report General Tools

- ASQ (Ages and Stages Questionnaire)
  - 2 to 60 months of age
  - Good parent teaching tool! (better than PEDS)
  - 10 – 15 min to fill out and score, 30 item questionnaire
  - Valid Tool: overall agreement across all questionnaires compared to "gold standard" diagnostic testing = 83%
  - 2SD ASQ delay = likely 1.5 or below SD delay on a "gold standard" diagnostic testing (Bayley Scales, Gessell, etc.)
  - Sensitivity: 0.70 – 0.90 (moderate – high)
  - Specificity: 0.76 – 0.91 (moderate – high)
  - Reliability (test-retest & interrater) = 94%

Parent-report General Tools

- ASQ (Ages and Stages Questionnaire)
  - Healthy Start typically uses it
  - Birth to Three has adopted it
  - Head Start has adopted it
  - Most common tool for participating ABCD (Assuring Better Child Development) practices nationwide
  - Oregon's EI/ECSE agencies use the ASQ for screening
- 3rd edition ASQ includes…
  - New 2 mo interval with a post-partum mood disorder question
  - New 9 mo interval (recently re-normed)
  - New general question about "behavioral concerns" on all intervals

Parent-report General Tools

- ASQ (Ages and Stages Questionnaire)
  - 6 domains = communication, gross motor, fine motor, problem-solving, personal-social domains
  - 6 questions per domain
  - 8 "yes" or "no" overall questions
- Typical Clinician ASQ interpretations
  - If 1 or more domain(s) delayed, then refer
  - If only 1 domain questionable, then refer based on clinician judgment (h/o pp depression?, prematurity?)
  - If 2 or more domains questionable, then many refer

Parent-report General Tools

- PEDS (Parents Evaluation of Developmental Status)
- Only 10 items! Same questions at each well-child visit
- Theoretically higher completion / return rates
- Feasible. Only 2- 10 min administration time!
- Easier to use along with the M-CHAT at 18 & 24 months compared to the ASQ
- For ages 0 – 8 years old
- Moderate sensitivity (0.74 – 0.79)
- Moderate specificity (0.70 – 0.80)

Parent-report General Tools

- PEDS (Parents Evaluation of Developmental Status)
  - Some questions are not always age appropriate…
    E.g. "Do you have any concerns about how your child is learning preschool or school skills?"… for a 9 month old???
  - If 2 predictive concerns?… then refer to EI/ECSE
    with or without audiological, mental health, educational testing
  - If 1 predictive concern?…then "screen or refer for screening"
  - Secondary screening in a busy clinic setting? Really?
  - Recent studies: some docs will and some won't refer to EI/ECSE for 1 predictive concern

Practitioner-based General Tools

- Denver II
- Most commonly used tool for kids 0 to 6 years
- Directly administered, observable tool
- Often not administered correctly
- Undesirable test-retest & interrater reliability
- Administration time is 10 – 20 minutes
- Low - high sensitivity (0.56 – 0.83)
- Low - high specificity (0.43 – 0.80)
- Most questionable results not referred so realistic sensitivity is low (56%) and specificity is high (80%)
- Unrealistic in a busy office practice

Parent-report General Tools

- PEDS:DM (Developmental Milestones)
- 6-8 items per age level, best used with the PEDS system
- Feasible for parents, clinicians (?*), < 5 minutes
- For ages 0 – (7-11) years old
- Each item taps into a developmental domain = great replacement for random developmental milestone reviews
- Moderate sensitivity and specificity (0.70 – 0.95)
- Validity data has been extrapolated from the Brigance
- *No clinical trials using PEDS:DM in a busy office setting
- The PEDS:DM binder has great supplemental screening tools but it's a bit bulky for clinician use in exam rooms.

Practitioner-based General Tools

- Bayley Infant Neurodevelopmental Screen (BINS)
- Not the Bayley Scales of Infant and Toddler Development- III
- Only for kids 3 – 24 months, studies were on kids 6 – 24 months
- Administration time = 5 – 10 min, not available in Spanish
- $325 for the kit + clinician training required
- Per manual, mod – high sensitivity (0.74 – 0.81) & specificity (0.7 – 0.79)
- Per clinical studies… sensitivity (range 0.64 – 0.82)
- Per clinical studies….specificity (range 0.42 – 0.87)
- Good for high-risk, low birth weight populations
- Doesn't fit the description of the 96110 CPT code
- What about kids > 24 months??

Parent-report Language Tools

- Language Developmental Survey (LDS)
- For children 1.5 – 5 years
- Administration time = 10 min, available in Spanish
- $65 for for 50 administration and scoring forms
- Per studies, sensitivity *mostly* mod – high (range 0.53 – 1.0)
- Per studies, specificity *mostly* mod – high (range 0.86 – 1.0)
- But… do you really want the LDS as a primary screen?
- Motor, problem-solving, personal-social and social-emotional delays all occur more frequently with language delayed children

Autism Surveillance & Screening

- Autism incidence 1:150 overall, 1:94 for males
- Autism Expert Panel– universally screen at 18 & 24 months
- 11/2007 AAP Autism Surveillance and Screening Algorithm scores 1 for each risk factor:

  a) Sibling with ASD, b) Parental Concern, c) Other Caregiver Concern,

  d) Pediatrician Concern
  - Score 0, universally screen at 18 & 24 mo
  - Score 1, autism-specific tool or "evaluate social-communication skills"
  - Score 2+, EI, Audiological & Comprehensive Evaluation Referrals + f/u office visit with the PCP within 1 month

Practitioner-based Cognitive & Language Tools

- Capute Scales: Cognitive Adaptive Test/ Clinical Linguistic Auditory Milestone Scale- Expressive and Receptive Language Scale (CAT/CLAMS)
- For infants and toddlers 2 - 36 months
- Administration time = 15 – 20 min, available in Spanish
- $350 for the kit + clinician training required
- Per studies… sensitivity *mostly* = mod – high (range 0.5 –1.0)
- Per studies… specificity *mostly* = mod – high (range 0.37-1.0)
- Good for high-risk, premature, low birth weight populations
- Doesn't fit the description of the 96110 CPT code
- Direct, observable tools are difficult at a busy clinic

Autism-specific Screening Tools

- CHAT (but variable sensitivity 0.18 –0.38, high specificity), CHAT-Denver Modifications, CHAT-23 (but 10 min), CAST (but for 4-11 yr olds), PDDST-II PCS (but 10-15 min), M-CHAT
- M-CHAT (Modified Checklist for Autism in Toddlers)
  - 16 – 48 months, recommended by all the experts
  - Sensitivity 0.85, Specificity 0.93
  - Available in Spanish
  - false (+) screens are likely still concerning, needing further assessment
  - Feasible: free, 23 items, 5-10 min, clear referral guidelines
  - 3 "failed" items = Refer
  - 2/6 critical items "failed" = Refer
  - Clinicians can do scoring, <10 seconds with a transparent scoring sheet

Does the ASQ “red-flag” Autism?

- Retrospective unofficial OHSU CDRC study, Dr Nickel
  - 45/46 (97.8%) autism spectrum d/o cases delayed in 1 or more domains on the ASQ

Why Screen Social Emotional Development?

- “Clear stages in emotional development in the first 6 years of life have been identified, disturbances at any of these stages influences the child’s present and the future adult’s attention, motivation, experience of pleasure, expression of affect, communication skills, style of interaction, and relationships with others.” - Greenspan, 1992

Social-emotional Surveillance & Screening

- AAP 7/2006 and Commonwealth Fund 3/2008 recommendations gave no guidance…. Why not?
- Some kids are “above cut-off” or “questionable” on a general developmental screen, but still evolve into a behavior disorder
- Part C of IDEA calls for the Social-Emotional area to be assessed and services provided if necessary.
- Programs such as Head Start mandate that this area be addressed in their performance standards.

Developmental-Organizational Framework (Cichetti, 1993)

Age	Stage of Development	Behaviors
0-12 months	Attachment	-regulation -recognizable states -attachment -communication
12-30 months	Autonomy & Self Development	-differentiates between self and others; real and make believe -use of pronouns exploration -self control; rules
30 months-7 years	Establishing Peer Relations	-empathy -gender differences -identification of friends -interest in other children

Why Screen Social Emotional Development?

1. EI for social-emotional problems is proven effective!
2. Links to early social emotional behaviors and subsequent outcomes suggest that intervention after 3rd grade is too late!
3. Red-flagging potential behavioral disorders helps pediatricians better target family counseling and utilize community resources
   - E.g. parenting classes, avoiding violent media, DV community programs, high-quality daycare or preschools
4. Primary care docs need to attempt to prevent, not primarily medicate behavioral disorders !

Social Emotional Tools: ASQ:SE

- BITSEA (12-36 mo), BABES (0-36mo), TABS (11-71mo) but…
- ASQ:SE = most effective, office-feasible tool (3-65 mo)
- 6,12,18, 24, 30, 36, 48 & 60 mo intervals but…
- E.g. 6 mo interval is really for kids 3-8 months of age.
- 22– 36 items per age interval
- 10-15 min to complete & score
- Areas = self-regulation, compliance, communication, adaptive behaviors, autonomy, affect, personal interaction

Social-emotional Research

1. Links between earliest emotional development and later social behavior. (Cichetti, 1993, Greenspan, 1992)
2. Links between early risk factors, poor outcomes & violence (Walker et al., 1996)
3. Behaviors, even in infancy, signal the need for intervention (DeGangi, 1991)
4. By third grade, programs for children with anti-social behavior are mostly ineffective (Walker et al., 1996)

Behavioral Areas	Definition
Self-Regulation	Ability/willingness to calm, settle, or adjust to physiological or environmental conditions
Compliance	Ability/willingness to conform to the direction of others and follow rules
Communication	Verbal/nonverbal signals that indicate feelings, affect, internal states
Adaptive	Ability/success in coping with physiological needs
Autonomy	Ability/willingness to establish independence
Affect	Ability/willingness to demonstrate feelings and empathy for others
Interaction with People	Ability/willingness to respond or initiate social responses with caregivers, adults,peers.

Social Emotional Tools, ASQ:SE

- Parent-friendly ASQ format with clear cut-off guidelines
- Sensitivity=70.8 – 84.6%
- Specificity=89.5 – 98.2%
- PPV=61 – 91% (PPV > 70% at 6, 12, 18, 36, 48, 60 mo)
- Be aware: culturally sensitive psychometric properties
- Concerning results?
  1. SE Development guides and Activity sheets for parents
  2. Refer to EI, mental health, high-quality daycare or preschool

Family Psychosocial Screening Tools

- WE CARE Survey (from Johns Hopkins)
- 10 (yes or no) questions
- If (+) concerns, does the parent want help?
  Yes___ No___ Maybe later___
- Then, at the end, rank your top 3 concerns for the doc
- Using this screen means a clinician <u>must</u> be prepared to refer to an appropriate community resource or refer back to the mother's PCP. Other option = arranging a f/u office visit.
- Found feasible by 200 parents and 45 residents at Johns Hopkins, A. Garg et al, *Pediatrics*, 9/2007

Family Psychosocial Screening Tools

- Pediatric Intake Form from Bright Futures
- For 2week WCC
- 2 pages, busy form with lots of questions
- Adapted from the Family Psychosocial Screen
- Can be scored but, unlikely to happen in primary care
- Great baseline information form
- Screens for parental depression, substance abuse, domestic violence, parental h/o abuse
- Identifies social supports

Post-partum Mood Disorder Screening Tools

- Post partum mood disorders
  - correlates to future personal-social, cognitive and social-emotional delays/ behavioral disorders
  - 24–50% paternal depression in the 1st postpartum year
- Favorites = EPDS, Beck II inventory, PHQ2, PHQ9
- 2 mo interval ASQ will have a well-crafted pp mood d/o question !

Post-partum Mood Disorder Screening Tools

- If (+) screen then…
- Refer to community maternal mental health resources
- Refer the mother (& send your clinic note) back to her PCP (ob/gyn, midwife, FP)
- Directly refer mom to a mental health provider

- Is universal screening feasible? YES!
- Is universal screening effective? YES! (detection rates in one's practice will typically double)
- But is screening moms really the pediatrician's job? YES!!!

Post-partum Mood disorder Screening Tools

Patient Health Questionnaire-2

1. Are you currently being treated for depression or anxiety? _ yes, _ no
2. Are you receiving counseling for depression or anxiety? _ yes, _ no
3. Are you taking medicine for depression or anxiety? _ yes, _ no
4. Since your new baby was born, how often have you been bothered by little interest or little pleasure in doing things?

   _ always, _ often, _ rarely, _ never
5. Since your new baby was born, how often have you been feeling down, depressed or hopeless?

   _ always, _ often, _ rarely, _ never

Post-partum Mood Disorder Screening Tools

- Edinburgh Postnatal Depression Scale (EPDS)
  - My personal favorite!
  - 10 items, a score $\geq$ 12 is concerning
  - EPDS universally at 2 months (refer if score is $\geq$ 12)
  - Repeat EPDS at 4 mo if score is $\geq$ 10
  - Must always look closely at question # 10!
    - "The thought of harming myself has occurred to me."
  - Mom completes EPDS & clinician does a better PE !
  - Because silence is a golden for the cardiac exam

Post-partum Mood disorder Screening Tools

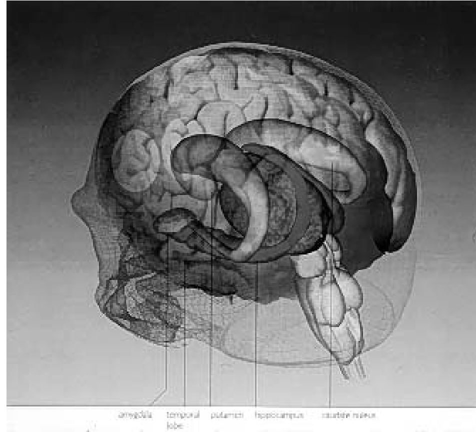
Patient Health Questionnaire-2

- ➢ Universally screen at 2 weeks and 2 months
- If the answers = "always" or "often", take action

- ➢ My problem with the PHQ-2 = anxiety is a more prominent feature w/ post-partum mood disorders than depression
- 3-item anxiety subscale from the EPDS is a better ultra-brief screen than the 2 questions on the PHQ-2

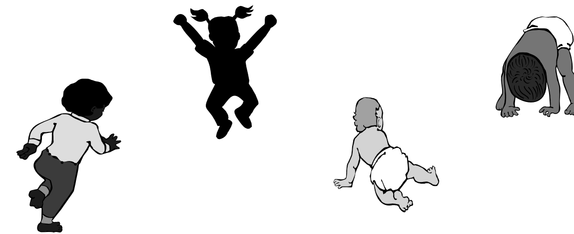
  -9/2008 *Pediatrics*, Kabir et al article

Now, what was our objective again???



The ASQ

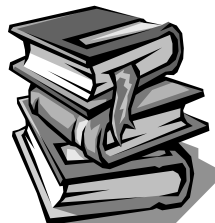
Back to the screen most clinics will be selecting…



Operation: "School Readiness"

"You teach a child to read, and he or her will be able to pass a literacy test."

- George W. Bush, Townsend, Tenn., Feb. 21, 2001



ASQ Implementation

- Can use an "in-office vs. mail-back" approach
- 30 minutes of training for staff. Ongoing process reminders.
- Resource staff scores the ASQ (unfortunately after the WCC)
- Itemized cost = $1.61 - $2.43 per patient. A medical bargain !
- Hemogram ($18) + lead level ($28) + Lab draw fee ($14) = $60 for comparison
- Cost varies on the mail-back option and clinician recommendations
- <u>Receptionist</u>, Nurse, Doctor all say:
  - "The ASQ is a fun and very important part of this well-child visit. We prefer you fill it out before your exam. If you don't have time, take it home & mail it in."

ASQ Implementation

1. Scheduler says: "come 15 min early to fill out the ASQ"
2. Frequently remind receptionists to get parents to complete the correct age-interval ASQ while in the waiting room!
3. Nurse double-checks to make sure they received the correct age-interval ASQ and that the parents filled it out the ASQ
4. Physician reviews ASQ, double-checks items marked "not yet"…"Did you ever try that task with your child?"
5. Physician quickly reviews the ASQ which helps to target the parent's areas of concern. This process alters the HX & PE.
6. ASQ is then scored by clinic staff, not by the clinician
7. Then ASQ is sent back to the clinician for interpretation
8. Resource staff then processes any needed referrals, orders

ASQ Clinician Recommendation Options

Clinicians need <u>standardized</u> recommendation options:

___ Observe, surveillance at next WCV

___ Give age-appropriate ASQ activity sheets to parents

___ Repeat ASQ in ____ (2-6) months

___ Refer to Early Intervention or Special Education Agency

___ Arrange a f/u office-visit for a repeat developmental-behavioral and medical evaluation in ____ week(s)

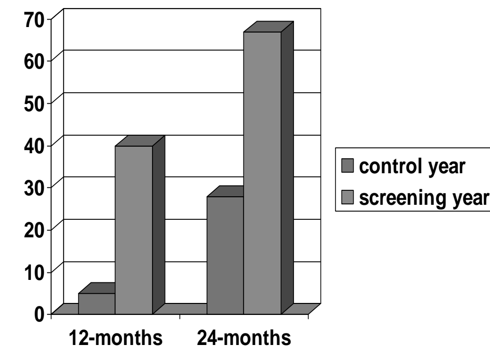
___ Other secondary developmental and/or medical referral =____

ASQ Quality Improvement Ideas

1. Time spent orienting & training staff saves time later. The goal = get the ASQ completed in the reception area.
2. Provide support for parents who need help filling out the ASQ
3. Higher return rates likely if the ASQ is completed in the office for Medicaid, younger (<21) and Spanish-speaking parents. Other parents can be allowed to mail it back from home.
4. Many photocopies of the 8, 10, 12, 16, 18, 20, 24, 36 mo ASQs!
5. ASQ icon on reception & nurse's computers to print an appropriate age-interval ASQ for late arrival well visits (e.g. 14 month old child who comes in for the 12 month WCC)
6. Online-ASQ will be a big leap forward for quality improvement.

ASQ Control and Screening Years Referral Rates Increased 224%

12 mo, 5--40 referrals (8X higher) 24 mo, 28--67 referrals (2.5X higher)



ASQ Study's Referral Data

- When pediatricians referred alone there was 92% agreement with the Part C agency's follow-up screening
- When pediatrician PDI and ASQ results indicated a delay, the Part C agency agreed 100% of the time!
- When the ASQ alone referred the case, the Part C agency agreed 63% of the time (Note: Oregon has strict EI-eligibility criteria)
- 25 (23%) did not qualify for further follow-up
- Implication: EI/ECSE agencies should strongly consider direct, observable, diagnostic testing on all pediatrician suspected delays, most especially if the ASQ is in agreement

Facilitating EI/ECSE Referrals

Standardized ASQ Referral Letter

1. Should state that development is a moving target and that early intervention has been proven to be beneficial. The ASQ shows a concern, not a diagnosis at this point in time.
2. Your child's normal and concerning areas of development are….
3. Your clinician and the AAP recommends this referral
4. A developmental agency will be contacting you shortly. You are welcome to call them at the following phone #____________
5. Enclosed are some fun ASQ activity sheets to play with your child
6. You are welcome to arrange a f/u visit with your doctor if you have any further questions or concerns

Facilitating EI/ECSE Referrals

- Parents need a standardized, reliable (2+ actions), interpersonal process to better facilitate EI, ECSE or other developmental agency referrals
- Ideal = referrals occur in "real-time" after the clinician has reviewed the ASQ's results + done a HX & PE + talked to the parent(s) face-to-face about the referral
- If the ASQ is scored & interpreted after the parent has left the clinic, then I recommend…

1. A parent-centered, standardized referral letter and…
2. A trained resource nurse phone call vs. a repeat office visit with a repeat HX & PE + clinician-parent conversation

EI/ECSE Referral Feedback

- Developmental agency feedback to clinicians should be considered mandatory for all referrals even if follow-up with the developmental agency was never established

✓ Was the child lost to follow-up?
✓ Did the parent(s) refuse services?
✓ Screened out?
✓ Monitoring?
✓ EI or special education eligible?
✓ Clinicians need to review diagnostic reports in order to identify medical conditions, developmental and/or behavioral disorders

Diligent Practitioner Surveillance

- If not receiving EI or special education services, clinicians should still provide diligent surveillance, especially if the child is higher-risk for a delay
- The clinician should lower their screening threshold if….

1. High psychosocial stressors, DV, poverty, h/o abuse or neglect, etc
2. Ex-preemie, low birth weight
3. Maternal depression/ mood disorder
4. In-utero drug, alcohol or tobacco exposure
5. FH of ASD, ADHD, LD, MR, Fragile X, bipolar, etc.
6. PMH that could adversely affect development or EI treatment plan (e.g. FTT, iron deficiency anemia, obstructive sleep apnea, etc.)

Kevin's Conclusions

- If you select the ASQ, supplemental universal 18 & 24 mo M-CHAT screening is likely not needed… but no published evidence yet
- If you select PEDS, supplemental universal 18 & 24 mo M-CHAT screening may also be needed… especially if there is only 1 predictive concern
- ASD ASQ profiles = 2SD delay in communication & personal-social domains + overall section will have (+) behavior and/or hearing concerns

Kevin's Conclusions

- Pediatric Intake Form (Bright Futures): at 2 weeks
  - Has the Family Psychosocial Screen built into it
- EPDS: at 2 months (repeat at 4 mo if score is $\geq$ 10)
- ASQ: as needed if parental developmental and/or behavioral concerns. When pediatrician concerns arise, then just refer!
- ASQ: universally at (9 vs. 12), 24 and 36 months.
- ASQ:SE: 18 (15-20) mo + 3-5 yrs universally + as needed if (+) "behavioral concerns" or high psychosocial concerns & the ASQ was "above cut-off"

Kevin's Conclusions

If using the ASQ, between 16 – 48 months …

- If 1 parent, clinician or "other caregiver" has autism / social communication concerns or (+) FH of ASD in a sibling…
- Then administer the M-CHAT
- If 2+ concerns (per the 11/2007 AAP ASD algorithm)…
- Then refer to EI + audiologist + comprehensive autism evaluation with a DB or ND pediatrician + f/u office visit in 1 - 4 weeks
- If (+) ASD ASQ profile…
- Then EI referral + M-CHAT & interactive ASD-targeted HX & PE at a follow-up office visit in 1-4 weeks

Future Directions

- A well-done, retrospective study of the ASQ and PEDS's detection of autistic spectrum disorder & pervasive developmental disorder cases is needed
  - ➢ How do we red-flag and expedite ASD referrals?
- Autism is a neuro-genetic (+/- fetal testosterone) disorder
- ASD genetic markers for prenatal screening, especially if (+) FH?
  - ➢ Identify high-risk CNTNAP2 mutation variations on chromosome #7….
- Then provide automatic, targeted EI before 9 months

CHADIS

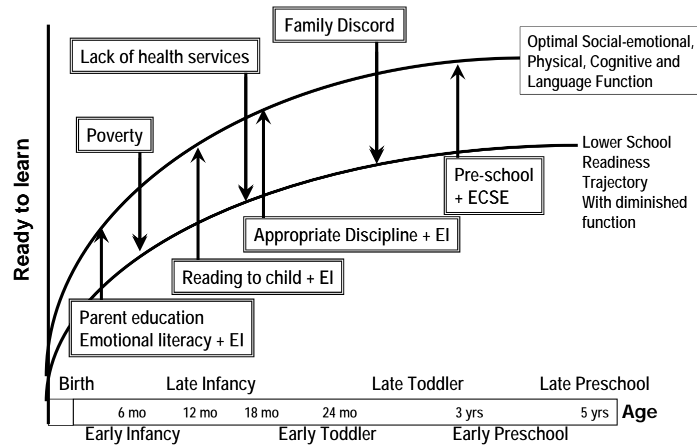
- ➢ From: Center for Promotion of Child Development through Primary Care (Drs Sturner & Howard, John Hopkins)
- ➢ Web-based, diagnostic management and tracking tool for children's behavior & development
- ➢ http://www.childhealthcare.org/chadis
- ➢ 25 different, valid and reliable screening tools !
- ➢ Includes the EPDS, ASQ, M-CHAT, Vanderbilt NICHQ behavioral assessment scales, Patient Health Questionnaire for Adolescents (PHQ-A), all the best "quality" screening tools
- ➢ $600 per clinician / year but saves $ long-term

The On-line ASQ !

- Voice synthesis capabilities in multiple languages to overcome both language and illiteracy barriers
- Embedded video demonstrates developmental tasks
- Automatically adjusts for prematurity in the first 2 years, as recommended by the Committee On the Fetus and Newborn (COFN) and guides parents to the correct age-interval ASQ
- Done at home or a quiet waiting room kiosk before or after targeted well-child visits
- If (+) behavior concerns, then ASQ:SE at next office visit
- Automatically scoring = no human scoring errors or need to utilize/ hire extra clinic staff

"But really, I'm not gonna make a difference. My clinic is <u>way</u> too busy to do screening and I can't change a family's genetic background or living situation."

- Think "outside the walls" of your office environment
- Utilize your community's early childhood resources!
- Promote appropriate discipline, parenting classes, reading and your local area's high quality preschools!
- Adopt a surveillance and screening schedule that works best for your clinic! NO MORE EXCUSES!


Strategies to Improve
School Readiness Trajectories
Family Discord
Lack of health services
Optimal Social-emotional,
Physical, Cognitive and
Language Function
Poverty
Ready to learn
Lower School
Readiness
Trajectory
With diminished
function
Pre-school
+ ECSE
Appropriate Discipline + EI
Reading to child + EI
Parent education
Emotional literacy + EI
Birth
Late Infancy
Late Toddler
Late Preschool
6 mo
12 mo
18 mo
24 mo
3 yrs
5 yrs
Age
Early Infancy
Early Toddler
Early Preschool