CONFERENCE GOAL

Exchange information on

• Early identification
• Developmental screening
• Referral and Response
Humans are not ideally set up to understand logic; they are ideally set up to understand stories.

Roger Schank, cognitive neuroscientist

Criteria for judging conditions appropriate for the screening process

- Must have significant morbidity or mortality and be sufficiently prevalent
- Screening program must include entire population
- Diagnostic tests must distinguish affected from non-affected persons
- Condition must treatable or controllable
- Detection and treatment during asymptomatic stage much improve prognosis
- Adequate resources must be available for definitive diagnosis and treatment
- Cost of screening must be outweighed by savings in suffering and alternative expenditures

**Criteria by which specific tests are judged appropriate for use in screening programs**

- Simple, convenient, acceptable
- Reliable, valid (sensitive and specific)
- Economical
- Lend themselves to easy interpretation
VALIDITY OF PARENTS’ APPRAISALS AND DESCRIPTIONS


INFORMATION AVAILABLE FROM PARENTS

- **Appraisals** (opinions of children’s development)
  - Concerns
  - Estimations
  - Predictions
- **Descriptions**
  - Recall
  - Report
PARENTS’ APPRAISALS

Concerns

- Accurate indicators of true problems
  - Speech and language
  - Fine motor
  - General functioning ("he’s just slow")
- Self-help skills, behavior less sensitive

"Please tell me any concerns about the way your child is behaving, learning, and developing”
- “Any concerns about how she…”
PARENTS’ APPRAISALS

Estimations

- “Compared with other children, how old would you say your child now acts?”
- correlate well with developmental quotients
  - cognitive, motor, self-help, academic skills
  - less accurate for language abilities

Predictions

- likely to overestimate future function
  - if delayed, predict average functioning
  - if average, “presidential syndrome”
PARENTS’ DESCRIPTIONS

Recall of developmental milestones

- notoriously unreliable
- reflect prior conceptions of children’s development
- accuracy improved by records, diaries
- even if accurate, age of achievement of limited predictive value
PARENTS’ DESCRIPTIONS

Report

• accurate contemporaneous descriptions of current skills and achievements

• importance of format of questions
  • recognition: “Does your child use any of the following words…”
  • identification: “What words does your child say?”

• produces higher estimates than assessment
  • child within a familiar environment
  • skills inconsistently demonstrated
Developmental Surveillance and Screening (AAP Policy Statement, July 2006)

- **Definition of surveillance**
  - Flexible, longitudinal, continuous process
  - Knowledgeable practitioners perform skilled observations during child health encounters

- **Components of surveillance:**
  - Eliciting/attending to parents’ concerns
  - Obtaining a relevant developmental history
  - Making accurate observations of children
  - Identifying risk and resiliency factors
  - Maintaining record of process and findings
  - [Sharing opinions with other professionals]

- View child **within context** of overall well-being
Developmental Surveillance and Screening (AAP Policy Statement, July 2006)

- Use of screening tools at periodic intervals to strengthen surveillance
  - Types
    - Parent-completed questionnaires
    - Professionally-administered “tests”
  - Frequency
    - 9, 18, 24-30 months
    - When concerns arise (“second-stage”)

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™

ASQ

Denver Developmental Materials
DEVELOPMENTAL SCREENING

Parent-Completed Questionnaires

- Advantages
  - ease of administration
  - do not require child’s cooperation
  - broad sampling of skills
  - flexible administration methods
    - mailed prior to visit
    - complete in waiting room
    - waiting room or telephone interview by staff
    - combination

ASQ

PEDS Response Form
DEVELOPMENTAL SURVEILLANCE AND SCREENING

• Expert opinion and research evidence support *developmental surveillance* as “optimal” clinical practice for monitoring children’s development (*Arch Pediatr Adolesc Med* 2001;155:1311-1322)

• Effectiveness is enhanced by incorporating valid measures of parents’ appraisals and descriptions (i.e., parent questionnaires) and/or objective measures of children’s development (i.e., professionally-administered tools)
  
  • *surveillance and screening*
  
  • *screening at 9-, 18-, and 24-30 month visits*
DEVELOPMENTAL SURVEILLANCE AND SCREENING

Caveat:
Detection without referral/intervention is ineffective and may be judged unethical
1990’S-“DECADE OF THE BRAIN”
CRITICAL CONCEPTS IN EARLY BRAIN DEVELOPMENT

- Proportional brain growth
- Neural plasticity
- Critical periods
- Sequential development
- Role of experience

Biology of adversity
- Toxic stress

The True Nature of Preventive Medicine

Death

Early Deaths

Disease & Disability

Adoption of Health-Risk Behaviors

Social, Emotional, and Cognitive Impairment

Adverse Childhood Experiences

Mechanisms By Which Adverse Childhood Experiences Influence Adult Health Status

Connecticut Children’s Office for Community Child Health
PLANNING PARTNERS

• Hartford Foundation for Public Giving (HFPG)  
  Brighter Futures initiative
• Hartford City Health Department  
  • Child Development Program (CDP)
• Region’s child health providers  
  • Community health centers
• Children’s Health Council  
  • Children’s Health Infoline
• Hartford Parents Network
• CT Birth to Three System (Part C)
SHARED ASSUMPTIONS

- Children with developmental/behavioral problems are eluding early detection
- Many initiatives exist to provide services to young children, their families
- A gap exists between child health and child development/early childhood education programs
- Children and their families would benefit from a coordinated, region-wide system of early detection, intervention for children at developmental risk
HELP ME GROW SYSTEM

Core Components

1. Child health care provider outreach to support early detection and intervention.

2. Community outreach to promote use of Help Me Grow and to provide networking opportunities among families and service providers.

3. Centralized telephone access point for connecting children and their families to services and care coordination.

4. Data collection to understand all aspects of the Help Me Grow system, including the identification of gaps and barriers.

Structural Requirements

- Organizing Entity
- Statewide Expansion
- Continuous Quality Improvement
Child Development Infoline, a specialized call center of United Way 2-1-1, helps families with children who are at risk for or experiencing developmental delays or behavioral health issues find appropriate services.

**Care Coordinators provide:**

- Assessment of needs & referrals to services
- Education on development, behavior management and programs
- Ongoing developmental monitoring
- Advocacy and follow up
Connecticut's Child Development Infoline
The Gateway to Help and Referrals for Parents, Providers, Pediatric Professionals
1-800-505-7000

Connecticut Birth to Three System
Birth to 36 months of age
For children birth-36 months of age with developmental delays or disabilities.

Help Me Grow
Birth through Age 8
For children birth through age 8 considered 'at-risk' for developmental or behavioral problems.

Early Childhood Special Education
Ages 3 through 5
For children ages 3 through 5 who are found eligible for special education services.

Children and Youth with Special Health Care Needs
Birth to Age 21
For children and youth birth to age 21 with chronic physical, developmental, behavioral, or emotional conditions who require more health and related services than other children the same age.

Participating Agencies
- Department of Education - Department of Developmental Services - Department of Public Health - Office of Early Childhood - United Way of Connecticut
• Promoting development and expansion of a national network of states that are building HMG systems
• Providing technical assistance to help states implement HMG’s core components and structural requirements
• Informing the public discourse on the crucial importance of optimal child development
• Providing tools for implementation
• Supporting the dissemination of innovations

Affiliates/Pre-Affiliates

Alabama
Alaska
California
Colorado
Connecticut
Delaware
District of Columbia
Florida
Iowa
Kentucky
Louisiana
Massachusetts
Michigan
Minnesota
Mississippi
Missouri
New Jersey
New Mexico
New York
Oregon
Puerto Rico
South Carolina
Utah
Vermont
Washington
West Virginia
Wyoming
<table>
<thead>
<tr>
<th><strong>Help Me Grow National Network</strong></th>
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<tr>
<td><strong>Diffusion of Innovations</strong></td>
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<td><strong>MLDA</strong></td>
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<td>(Mid-Level Developmental Assessment)</td>
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<td><strong>CCC</strong></td>
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<td>(Care Coordination Collaborative)</td>
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Mid-Level Developmental Assessment

Comprehensive Global Developmental Assessment

- More than Developmental Screening
- Less intensive than full multidisciplinary/tertiary level Evaluation
- Process and Procedures with formal developmental assessment measure(s) that integrates and builds
Care Coordination Collaborative

Coordinating the Care Coordinators

• **Core Components**
  1. Formal/informal convenings of care coordinators from diverse programs and services
  2. Support to child health services providers
  3. Common access to central portal of entry to programs and services
  4. Data collection and dissemination (to map partnerships, system building)

• **Structural requirements**
  1. Organizing entity
  2. Regional/statewide reach/impact
  3. Data-informed CQI activities
Collaborative Progress Towards the SMART AIM

Ave % of children with developmental or behavioral concerns identified receiving services in a timely manner
SMART AIM is a Cumulative Sum of:

Ave % children referred for EI who received evaluation within 60 days

Ave % children referred to community services who received services within 30 days

Ave % children with parental concerns or positive screen not referred to EI or community svcs receiving individualized developmental support from HV
### Primary Drivers

**PD1. Reliable and effective systems for surveillance & screening**
- Identification of appropriate developmental and behavioral screening instruments, applied correctly
- Periodicity to capture key milestones
- Screening conducted within context of surveillance
- Screening results interpreted in context of all HV knows about family/ environment
- Timely, specific and sensitive communication of results to families

**PD2. Reliable and effective systems for referral & follow-up**
- Strong links and care coordination community partners and resources
- Closed loop of communication for +screen: referral, access, feedback

**PD3. Home visitors supported to address development in the target population**
- Home visitors with knowledge of state’s comprehensive early childhood system & processes
- Home visitors with knowledge and competency in developmental and behavioral surveillance, screening, sharing results, anticipatory guidance, referral and follow up
- Use of data to improve practices
- Timely and Effective Supervisory Support

**PD4. Engage Families in Promotion of Healthy Development**
- Families’ direct impact on development supported & maximized (through stimulation, strengthening of protective factors, etc)
- HV engages family-led conversation regarding development at every home visit
- Referrals & linkages HV recommends are acceptable to family (geographically, culturally appropriate)

### Secondary Drivers

- Specific Ideas to Test or Change Concepts
  - C1. Protocol for surveillance and screening standards (tools, periodicity, referral, follow-up)
  - C2. Tracking system for surveillance, screening & referral
  - C3. Regular training for HVs on policy and protocols, practices and use of tools
  - C4. Parent views/concerns about child’s development elicited and addressed at each home visit
  - C1. Program develops formal connections with community services (i.e., MOU’s)
  - C2. Developmental & behavioral screening passport (0-5, Watch Me Thrive!)
  - C3. Protocols or decision tree for for process of red flag/positive screen, referral and follow up
  - C1. Training/education of HV’s in Dev, systems & best practices
  - C2. Ongoing supervision on use of surveillance and screening (e.g., video-recordings of screenings using ASQ/ASQ:SE)
  - C3. Home visitor has access to their own data for use in QI
  - C4. Support for supervisors in screening process
  - C5. Reflective and administrative Supervision
  - C1. Anticipatory guidance & education to families about development based on screening process
  - C2. Protocols for addressing parent concern with home visiting activities
  - C3. HV seek feedback from parents on use of referred services
Process AIMS were set to capture our improvements in the process of developmental promotion, early detection and intervention.
Developmental Promotion, Early Detection, and Intervention Learning Collaborative
CONCLUSIONS-IMPLICATIONS

• The evidence-based, expert recommended process for early detection is developmental surveillance and screening
  • *Parent engagement* key to process

• Referral and linkage to programs and services is a major challenge
  • Demands a *systems approach* (e.g., Help Me Grow)

• Early childhood system building may be best framed as a Developmental Promotion, Early Detection, and Intervention CoIIN
REFERENCES


