

# FIVE STEPS FOR SUCCESS: AUTISM DIAGNOSIS EDUCATION PILOT PROJECT

*A Project of the Ohio Chapter of the American Academy of Pediatrics (OAAP)  
Funded by the Ohio Department of Health Bureau of Early Intervention Services*

**1. Engage primary care health professionals in continuing education that will lead to implementation of enhanced developmental surveillance, and use of standardized developmental screening tools, including tools for autism, following American Academy of Pediatrics guidelines.**

## **A. Developmental Surveillance and Screening Practice-Based Collaborative**

- a. Identify pediatric and/or family medicine practices in each of 5 target regions (Belmont, Cuyahoga, Franklin, Warren and Wood Counties) to participate in a 10-15 hour longitudinal CME program that will provide participants with the knowledge, skills, and ongoing support to successfully implement developmental surveillance and screening, and enhance community linkages in their practices.
  - a. IRB approval will be requested at Cincinnati Children's Hospital Medical Center and Akron Children's Hospital.
  - b. Nursing CEU and Medical CME will be applied for through Akron Children's Hospital.
  - c. Practices in the target counties will have first priority. Practices in adjoining communities/counties will be secondary priorities.
    - i. Practices will be asked to form teams that include a physician, nurse/medical assistant, manager, and a parent.
  - d. Incentives for participation will be developed and promoted.
    - i. Satisfaction in making an organized commitment to enhancing the quality of care offered to families in the practice.
    - ii. A free ASQ kit
    - iii. Certification of participation for display in the practice's office, on their web site, and in their office materials.
    - iv. Special recognition on the Ohio AAP website.
      - A. Special listing as practice that has completed the program and made a commitment to developmental surveillance and screening
      - B. A one week feature on the home page of the Ohio AAP website for each practice that participates.
    - v. Enhanced income from completing standardized developmental screening.
  - e. Recruitment of participants
    - i. The Ohio AAP website, Ohio Pediatrics news magazine, blast emails, and electronic newsletters from the Ohio AAP, Ohio Pediatric Research Coalitions, OAFP, and Ohio Osteopathic Association will be utilized to notify practices of the program.
    - ii. Members of the **Expert Panel**, especially the medical experts, will be asked to make personal contact with colleagues in primary care to invite them to participate.
    - iii. OAFP members of the Advisory Board will be asked to assist in recruitment of family physicians.
  - f. Participation in the program will meet requirements for Maintenance of Certification for the American Board of Pediatrics and the American Board of Family Medicine, which will be required in 2010.

- g. Proposed Agenda for Learning Sessions:
  - i. Evening
    - A. Storyboard reception with food
    - B. Registration and Storyboard Setup
    - C. Welcome and Introductions
    - D. Review of State Efforts and ADEPP objectives
    - E. Why screen for developmental problems, including autism?
  - ii. Full Day
    - A. Registration
    - B. Welcome
    - C. Review of Data collected by practices as pre-work.
    - D. Introduction to Screening
      - a. Surveillance vs. Screening
      - b. AAP Recommendations for developmental surveillance and screening, including for autism.
      - c. Importance of early intervention
    - E. Tools and Methods
      - a. Administration and scoring of ASQ and M-CHAT
      - b. Case Study
    - F. Integration into the Workflow
    - G. QI Strategies-Models for Improvement-Designing Small Tests of Change
    - H. Measurement for Improvement-Ongoing data collection
    - I. The Parent's Perspective
    - J. Referral process
      - a. Introduce local providers/teams
      - b. Connecting with HMG, EI, Schools, MRDD, BCMH, case management, etc.
    - K. Billing and Coding
    - L. Team Planning Time
    - M. Wrap up and Next steps.
      - a. Calls with Diagnostic Partnerships
      - b. **Experts** on a listserv
      - c. Implementation Conference calls
        - i. 4 per month on same topic
        - ii. Roll taken
- h. Members of the **Expert Panel** will be invited to contribute to the development of content for the CME programs, participate as faculty at the CME programs in their regions, and participate as faculty for 4 monthly conference calls to support practices in implementation. There will also be a conference call prior to the learning session.
- i. The content for all five regional trainings will be the same.
- j. The Collaborative will promote a simple, consistent developmental screening protocol statewide.
  - i. Recommend developmental surveillance at all health supervision visits.
  - ii. Recommend use of the Ages and Stages Questionnaire at 9 months, 18 months, and 30 (or 24 months).
  - iii. Recommend use of the M-CHAT at 18 months and 24 months.

- iv. Encourage sharing of developmental screening results between health care settings, Help Me Grow, child care, Head Start, and preschool settings.
- v. Opportunities for enhancing community linkages will be identified in the program.
  - 1. Community providers will be invited to participate in the program.
- k. Collaborative quality improvement methods will be integrated under the guidance of the Cincinnati Center for Health Care Quality.
  - i. Practices will be asked to perform baseline and periodic chart reviews to check for evidence of:
    - A. Developmental surveillance: documentation of eliciting parents' concerns
    - B. Use of a structured developmental screening tool at 9, 18, and 24 months.
    - C. Use of an autism screening tool at 18 and 24 months.
    - D. Use of a tracking system for those identified at risk or who fail a screen.
    - E. Evidence of linkage to community resources
    - F. Percent of practice team who report that developmental screening is done effectively and efficiently in the practice
    - G. Percent of practice team who feel that families are satisfied with the practice's approach to developmental surveillance and screening.

**2. Identify, educate, and support community-based primary care practices who will partner with early intervention and early childhood education assessment teams in their communities to offer a standardized, comprehensive diagnostic evaluation for children with concerns in language and social development, including autism.**

**Community-Based Autism Diagnostic Partnerships**

- A. Recruit practices in each of the 5 target communities to participate in a 1 day CME program to develop the knowledge and skills necessary to perform a comprehensive differential diagnosis of social and language delay in early childhood, including autism.
  - a. Learning objectives will be:
    - i. Develop skills in interpretation of a comprehensive developmental assessment, including the ADOS.
    - ii. Enhance skills in obtaining and documenting developmental history (including age at initial concern), and physical/neurological examination, including dysmorphology exam.
    - iii. Use evidence-based tools to screen for parental depression, alcohol use, and domestic violence.
    - iv. Assure that all children are referred for vision and hearing evaluations. (prior to visit)
    - v. Enhance skills in sharing developmental diagnosis, prognosis, genetic counseling, and treatment planning with families.
    - vi. Enhance skills in selecting and recommending genetic testing, brain imaging, and electroencephalographic studies in appropriate cases.
  - b. Members of the **Expert Panel** will be asked to assist in development of curriculum and presentation at the training.
  - c. Members of the **Expert Panel** will be asked to assist in providing ongoing technical support to the medical practitioners.
  - d. Examine feasibility of having all practices be BCMH diagnostic providers. Enroll all patients for BCMH Diagnostic evaluation.

- B. Recruit early intervention and early childhood education specialists who will partner with the medical practices to offer a standardized, comprehensive assessment for children with concerns about language and social development, including the possibility of autism. The assessment will include:
  - 1. A measure for all developmental domains, including cognitive functioning
    - a. Bayley III or Battelle Developmental Inventory, or Mullen Scales of Early Learning
  - 2. A measure of adaptive behavior
    - a. Vineland Scales Parent form or SIB-R
  - 3. An Autism specific diagnostic assessment: ADOS
    - a. Identify the needs for ADOS training and arrange for attendance at the Akron Children's Hospital/Western Psychological ADOS training on 8/7-8/8/08.
  - 4. A speech and language/communication assessment
  - 5. An observation of parent-child interaction
  - 6. A routines-based interview
    - a. McWilliam RA, INTEGRATE Model for Natural Environments in Early Intervention
    - b. [www.waisman.wisc.edu/birthto3/WPDP/txt/rbi.html](http://www.waisman.wisc.edu/birthto3/WPDP/txt/rbi.html)
  - 7. An assessment of family psychosocial functioning
    - a. Family Quality of Life Scale,
      - i. Poston, D., Turnbull, A., Park, J., Mannan, H., Marquis, J., & Wang, M. (2003). Family quality of life outcomes: A qualitative inquiry launching a long-term research program. *Mental Retardation*, 41(5), 313-328.
      - ii. [http://www.beachcenter.org/resource\\_library/beach\\_resource\\_detail\\_page.aspx?intResourceID=2391&Type=Tool](http://www.beachcenter.org/resource_library/beach_resource_detail_page.aspx?intResourceID=2391&Type=Tool)
  - 8. Members of the **Expert Panel** will be asked to assist in providing ongoing technical support to the medical practitioners on a monthly basis.
  - 9. Members of the **Expert Panel** will be asked to assist in development of curriculum and presentation at the training.
- C. A single training for all teams will be held in Columbus.
- D. All teams will be asked to report their assessment findings, final diagnosis, and treatment plan in a web-based, secure, centralized database.
- E. Families who complete the comprehensive assessment will be asked to complete the Family Quality of Life Scale 6 months after initial referral as an outcome measure.

**3. Develop stand alone educational opportunities specifically for residents in pediatrics and family medicine, but made available to other health professionals as a member benefit.**

- A. In collaboration with OCALI, develop 3 interactive, web-based modules:
  - a. Developmental surveillance and screening, including autism
  - b. Differential diagnosis of delayed language and social development, including autism.
  - c. Supporting children and families affected by autism spectrum disorders in the medical environment.
- B. Develop and offer Grand Rounds on Developmental Surveillance and Screening, including Autism.
  - a. **Expert Panel** and a Local Expert Practitioner will be asked to give a Grand Rounds in all of the Pediatric Centers in Ohio by March 31, 2009.
  - b. **Expert Panel** and a Local Expert Practitioner will be asked to give a Grand Rounds in 5 of the 23 Family Medicine Centers in Ohio by March 31, 2009.
    - i. University of Toledo

- ii. Clinton Memorial
  - iii. MetroHealth
  - iv. Riverside
  - v. One other of the remaining of the others near the target communities
- C. Collaborate with professional organizations to disseminate these opportunities.
- a. Ohio Chapter, American Academy of Pediatrics
  - b. Ohio Academy of Family Physicians
  - c. Ohio Osteopathic Association
  - d. Ohio Chapter, National Association of Pediatric Nurse Practitioners
  - e. Ohio Association of School Nurses

**4. Work with the Ohio Department of Jobs and Family Services Bureau of Child Care, Healthy Child Care Ohio, the Ohio Child Care Resource and Referral Association, and local providers to identify and develop opportunities for collaboration to promote Step Up to Quality, including implementation of developmental screening in child care settings, while enhancing communication between child care providers and health professionals. In addition, identify strategies to enhance communication regarding developmental screening and concerns between Head Start and other preschool providers, and health professionals.**

- A. Explore the feasibility of co-hosting a developmental screening day that could include mini-talks by senior pediatricians in the area.
- B. Utilize data collected at focus groups to guide choice of media and the type of information to be offered.
- C. The campaign will be disseminated after March 2, 2009 to allow other components to be in place and be ready to respond to the public's requests.

**5. Develop and disseminate a public awareness campaign to promote the importance of addressing developmental concerns early and the value of early and repeated developmental screening, including for autism.**

- A. Work closely with NASHP team that completed focus groups with parents to identify how they want to receive information.
- B. Assure that web-based materials have links on sites where families already go.
- C. Utilize data collected at focus groups to guide choice of media and the type of information to be offered.
- D. The campaign will be disseminated after January 1, 2009 to allow other components to be in place and be ready to respond to the public's requests.

