

National Conversation
Developmental Screening and Referral
Promising Practices for Coordination of Services
June 21, 2007

Questions and Answers

Questions for Dr. Rosenberg / EDOPC Project (ICAAP, Advocate Health Care, Illinois Academy of Family Physicians, Ounce of Prevention Fund)

David Childers Asked: Dr R- Do you have a program/road show to help other states develop a similar program?

Dr. Rosenberg / EDOPC reply: The EDOPC project does not currently have funding for trainings outside of Illinois. However, we have gone to three other states to offer trainings at the expense of the sites. If you have specific questions, the project staff will be happy to help you individually. Please contact us at info@edopc.org. Also, FYI: The National Academy of State Health Policy (NASHP) is currently running a "Screening Academy" with 20 states to help them start developmental screening programs. If your state has a team participating, you should find out who the key players are. If not, nearly all of the resources are available to states or other groups looking to start such programs at www.abcdresources.org. (This is a Web site where materials and strategies from the NASHP/Commonwealth Fund Assuring Better Child Health and Development, or ABCD, project are posted.)

Robin Adair Asked: For Dr. Rosenberg: Of the 33 faculty for EDOPC, how many were physicians and how many were other professions (what and how many)?

Dr. Rosenberg / EDOPC reply: We have an additional 3 speakers trained on our 2007 faculty roster (for a total of 36). There are 24 MDs, 4 PNP's, 5 RNs and 3 Master's level faculty members (with degrees in Early Childhood Education).

Robin Adair Asked: Of the physicians, how many were primary care providers and how many were dev-behaved, or other

Dr. Rosenberg / EDOPC reply: 7 of the faculty members are dev-behavioral pediatricians

Lola Jahnke Asked: Who does this training to physicians?

Dr. Rosenberg / EDOPC reply: Please see the answer above. Presentations are offered by trained healthcare providers, including project staff, who obtain scripts of the presentations and participate in speaker training. Training is also offered through teleconferences and grand rounds.

Mary Pavan Asked: To Rosenberg: How did you get buy-in from Medicaid? Did you collect data about the number of children and families who were impacted? How frequently did the MDs who were trained use the screening tools? Who did the visits to the MDs?

Dr. Rosenberg / EDOPC reply: We are fortunate to have a great working relationship with the IL Medicaid program. This began with the publishing of the Unmet Needs project by the University of Illinois at Chicago and the Erikson Institute. The data from that project made it clear that the social and emotional needs of children were not being identified by the current primary care approach to the preventive visit. We further identified reimbursement as a critical factor in Medicaid participation as well as the specifics of early childhood. Now Medicaid reimburses for screenings and informs their providers about our training opportunities. We are currently working with Medicaid to cross check claims data to see if trained practices are billing for screenings. We also do chart reviews with a fifteen sites including Federally Qualified Health Centers, residency programs, and participating practices to assess whether screenings are implemented into practice following our training. We figured out approximately how many 0 to 3 year olds an average provider sees and at this time feel over three years we will have impacted about 20% of the children in our state. The MDs and their teams who were trained screen a minimum once in the first and once in the second years of life for developmental delays, once in the second year of life for social emotional delays or concerns, once in the first six months of life for perinatal depression. Most sites are able to easily implement more than this and do so once they have the system in place. See above for who offers the presentations in the practices. NOTE: in addition to trainings, we provide technical assistance to sites through teleconference, email, phone and on site follow up meetings and visits on an as needed.

Susan Sullivan Asked: Please explain the Academic Detailing Model from Dr. Rosenberg's presentation. What does that mean?

Dr. Rosenberg / EDOPC reply: *Academic detailing – also referred to as practice-based or office-based education – has gained ground as a means of delivering effective education. Physicians are facing increasing pressures and finding time to attend traditional conferences and hospital events can be difficult. Presenting programming at the site where health care is delivered is interdisciplinary in that it enables the sponsor to reach all health professionals and office staff involved in the delivery of care. It also facilitates personalization of the content and its recommended techniques to the actual processes employed in the host health care center, making the intervention relevant to clinical practice. For the physician, the challenges of adapting information received through continuing education to the practice setting and educating practice colleagues unable to participate in remote events is greatly reduced through the practice-based approach. Practice-based education programs not only provide speakers with insight into application of the curriculum in each practice environment but also allow them to identify new challenges and strategies that can then be incorporated into the presentation itself. An additional benefit concerns the ability to do practice-based research; initial data collection (chart reviews, environmental assessments) as well as education on the practice staff's roles in terms of data collection and reporting can occur in conjunction with the academic detailing visit. Academic detailing is one of the few educational interventions that has consistently demonstrated improved physician performance, and many studies show the positive impact of academic detailing as a model for physician behavior change.*

Christopher Kus Asked: Regarding EDOPC, do you have any data showing that the level of developmental screening has increased as a result of your efforts?

Dr. Rosenberg / EDOPC reply: *See above regarding chart reviews and our efforts to obtain data from Medicaid. The project's chart review data show most practices go from 0% screening to 85% screening in the first year. This generally happens gradually: after three months about 30% are screening, after six months: 50%, and then some practices go to up to 75% after nine months and 85-100% at a year.*

Sharon Reddick Asked: How much time needed to conduct the academic detailing; is this an hour presentation; more?

Dr. Rosenberg / EDOPC reply: *Ideally, we have 1.5 hours to offer the presentations. This allows plenty of time for the presentation, the videos incorporated into the talk, as well as Q&A. However, it's often difficult for busy practices to allow for this much time, so we are usually able to cut presentations down to an hour, if necessary, without sacrificing much of the content.*

Kathy Keitzer Asked: Do you have recommendations for specific tools, especially for other languages and cultures?

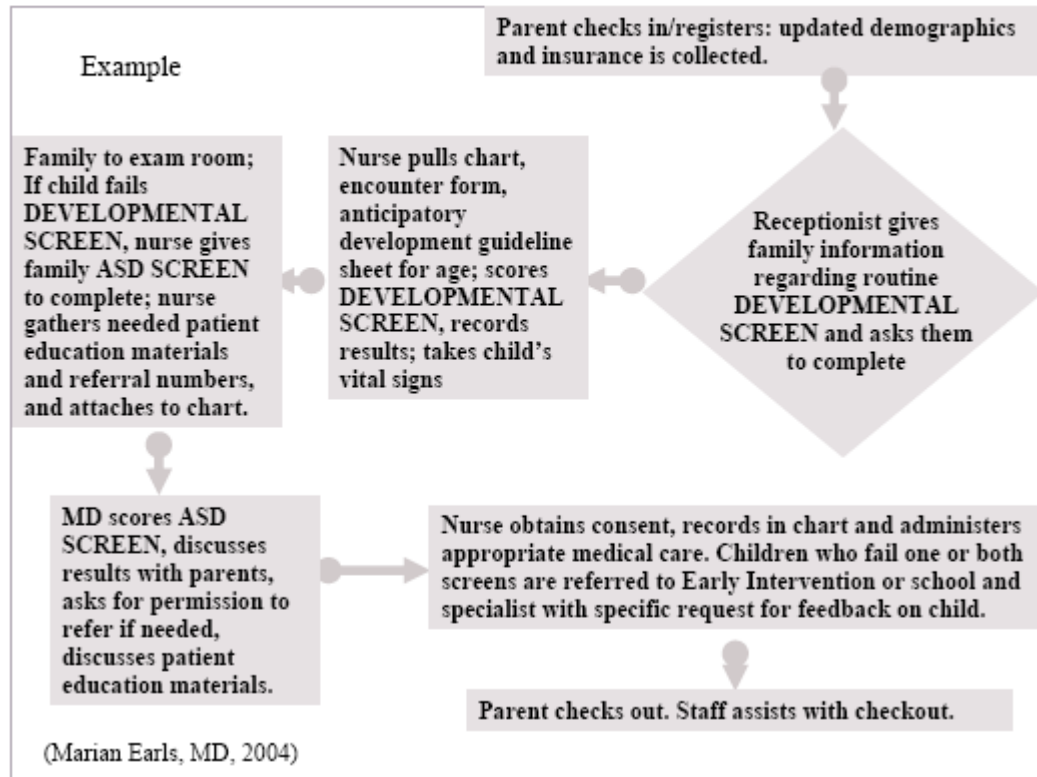
Dr. Rosenberg / EDOPC reply: *We teach the ASQ, the ASQ: SE, the Edinburgh Postnatal Depression Scale and the PHQ-9. Many screening tools, including those just listed, are available in multiple languages. Each practice decides which screening tools to use at specific ages, although we do make minimum guideline recommendations as noted above. We recommend following the PDSA cycle of PLAN DO STUDY ACT. Approaches may be tested and evaluated in the practice and when necessary a different screening tool is used.*

Marge Troester Asked: T Dr. Rosenberg- Do you find that there are limitations to Ages and Stages screenings due to parent over or under reporting? How do you integrate an objective screening tool into a busy practice?

Dr. Rosenberg / EDOPC reply: *We address the issue of "sometimes" in the Ages and Stages Questionnaire and encourage physicians to use this as a sounding board for discussion regarding the child's development. Studies show that parent report can be as accurate as more extensive provider screening and evaluation; however, we know there are certain population who would be more likely to try to answer "correctly" verses honestly, such as those being followed by child protective services, teen parents. We work with practices on how to work with these populations. We offer many tips on how to incorporate screening into a busy practice, including how to utilize the entire office staff (whom we encourage to attend the presentations) in order to offer a team approach to screening.*

Nancy Wiseman / PA CADDRE reply: *Even though screens may over-refer children, typically these are children that still need help from Head Start, remedial reading, or other supports. Following is an example of how to integrate screening into a busy office practice:*

Primary Care Screening and Referral Practice Flow



Fran Basche Asked: Any ideas about how to pay for developmental screening?

Dr. Rosenberg / EDOPC reply: *Illinois Medicaid and a limited number of other third party payors pay for the use of developmental screening tools with the code 96110. The reimbursement is about \$14.00. A number of other state Medicaid agencies also pay for developmental screening. Many practices do not bill the patient if the insurer does not pay for the use of a developmental screening tool. Many private insurers consider the developmental screen a part of a bundled service within the scope of preventive care.*

Carol Lilly asked: Do you have specifics regarding your negotiation with Medicaid that can be used by other areas as talking points?

Dr. Rosenberg / EDOPC reply: *The Unmet Needs project provided data that supported the need for attention to the social and emotional needs of children. There is ample evidence that by supporting families and the needs during the early childhood years that children grow up healthier and lead more productive lives. We believe that we can identify developmental challenges at earlier ages and intervene appropriately. The National Academy for State Health Policy's ABCD Web site has materials on "making the case" at <http://www.abcdresources.org/Activities/background.html> and information on improving policy at <http://www.abcdresources.org/Activities/improvingpolicy.html>. Staff at NASHP may be able to direct people to more specific talking points.*

Questions for Nancy Wiseman / PA CADDRE

Dan Riordan Asked: How much money was spent on the CADDRE program?

Nancy Wiseman / PA CADDRE reply: *The Pennsylvania First Signs Program cost \$330,000.*

Dan Riordan Asked: What is the impact on service providers once the numbers of referrals increase?

Nancy Wiseman / PA CADDRE reply: *It is too soon to know what the impact in Pennsylvania will be, however, every state is mandated to provide Early Intervention services; so if the numbers increase, the state must request additional funding to meet the demand*

Cori Hill Asked: Does PA (as a state) provide a recommendation on the number of hours of supports and services for children B-3 with ASD? Thanks!

Nancy Wiseman / PA CADDRE reply: *Pennsylvania has no specific guidelines. The number of hours of supports and services vary as every child is different. In some states (e.g., Pennsylvania and Massachusetts), a child is eligible for more intensive intervention services if they have a diagnosis of ASD.*

Debra Wagler Asked: Is there potential to sign up for First Signs, Inc. training to come to our state?

Nancy Wiseman / PA CADDRE reply: *Any organization can contract with First Signs to conduct trainings and/or outreach workshops, as well as implement a statewide First Signs program in your state. If you are interested, please contact First Signs at info@firstsigns.org.*

Questions for Evelyn Shaw / NECTAC:

Dan Riordan Asked: How are these new requirements funded?

Evelyn Shaw / NECTAC Reply: *Part C of IDEA is a grant program through the US Department of Education, Office of Special Education Programs. Part C money is awarded to state lead agencies through a grant application and approval process. Part C appropriations are set by Congress in their budget process. For fiscal year 2006, appropriations are \$436.4 million. Annual funding for each state is based upon census figures of the number of children, birth through 2, in the general population. State lead agencies must assure that services are coordinated with all other federal and state programs. Part C was intended to assist states and was not intended to fully pay for services and supports; Part C money is considered the "payor of last resort". To date, there have been no additional funds allocated through Congress to address these new requirements.*

Lucy Gibson Asked: What is the advantage of a child continuing to be served by Part C after age 3 as opposed to being served by Part B?

Evelyn Shaw / NECTAC Reply: *The Congress intended for IDEA 2004 to "establish a 'seamless system' for infants, toddlers, and preschoolers with disabilities. [The] new option added to Part C creates flexibility that gives families the option of continuing early intervention services from age 3 through enrollment in kindergarten instead of starting Part B preschool services." From "Key Changes in Individuals with Disabilities Education Act (IDEA) 2004 Amendments", Committee on Education and Labor, US House of Representative, see: <http://edlabor.house.gov/publications/IDEA2004keychanges.pdf> For other resources on the Part C Option, see NECTAC web resources: <http://www.nectac.org/~calls/2005/partcoption/optioncall.asp>*

Questions Open for All Presenters and Planning Team:

Fran Basche Asked: Any ideas about how to pay for developmental screening?

Nancy Wiseman / PA CADDRE reply: PCPs should submit to insurance for reimbursement. Following are CPT codes for screening:

96110 Developmental Screening (requires a validated tool)

96111 Extended Developmental Screening* (for second-stage screening and assessment)

96114 Neurobehavioral status exam**

99202-99205 E&M***, Office Procedural Codes, new patient

99212-99215 E&M***, Office Procedural Codes, return patient

99420 Administration and interpretation of health risk assessment****

* Applies to narrow/follow-up measures such as autism screening

** Usually results in higher reimbursement and should be reserved for standardized developmental screening as opposed to checklists, informal observation, etc.

*** E&M indicates evaluation and management

**** Behavior screening

The Center for Medicaid and Medicare guarantees reimbursement for the 96110 (broad-band screens) and 96111 procedure code (narrow-band screens and assessments) unbundled from the well visit via -25 modifier on the preventative services code. The average reimbursement rate is about \$10.00 nationally. Private payors generally follow Medicaid policy and most now reimburse for 96110. Denied claims should be appealed. The AAP has an office on billing and coding (Lwalsh@aap.org) and encourages providers to alert them if appeals are denied. (Glascoe, 2007)

Peggy Stemmler Asked: Once a child is identified at risk, what temporizing resources are available during the long wait for the EIP evaluation?

Evelyn Shaw / NECTAC Reply: Part C regulations require the assignment of a service coordinator upon referral of a child to Part C. Service coordination includes the identification and coordination of services across agency lines. During the 45 day timeline period (from referral, evaluation and assessment for eligibility and the initial IFSP meeting), services may commence before the completion of the evaluation and assessment whenever an immediate need for early intervention services is identified. Parental consent must be obtained, an interim IFSP is developed including the name of the service coordinator who will be responsible for the implementation and coordination of services on the interim IFSP and evaluations and assessments are completed within the 45 day timeline.

Kathy Keitzer Asked: Do you have recommendations for specific tools, especially for other languages and cultures?

Evelyn Shaw / NECTAC Reply: NECTAC developed a mini-bibliography on "Early Identification of Culturally and Linguistically Diverse Children (Aged 0 – 5)" in December 2005. This is available on-line at <http://www.nectac.org/~pdfs/pubs/earlyidmini.pdf>

Nancy Wiseman / PA CADDRE reply: The following recommended screening tools are available in English and other languages:

Ages & Stages (Spanish, French)

PEDs (Spanish, Vietnamese, Somali, Arabic)

CSBS DP Infant-Toddler Checklist (Spanish)

M-CHAT (Spanish and Chinese)

ASAS (Spanish)

SCQ (Spanish)

BITSEA (Spanish, French, Dutch, Hebrew)

Linda Tuchman/Waisman Center, NMHAI: One of the reasons that the ASQ is widely chosen as a screening tool is the responsiveness to other cultures. The norms for the tool were derived from diverse cultural groups. In advance of selecting a tool, I would encourage you to examine the administrative guide of the tool for information about the population(s) on which the norms for the tool were established. This will help you determine if the tool is appropriate for the children you aim to screen. You would want to see a good fit prior to selecting the tool.

Deborah Greenleaf Asked: What do you recommend for screening tools for infants birth to 4 months (before the ASQ)

Nancy Wiseman / PA CADDRE reply: *Either the Infant Development Inventory (IDI) for children 0-18 months or the Functional Emotional Assessment Scale (FEAS) for children 0-42 months.*

Maria Bravo Asked: What suggestions do you have for connecting parents/families of children with special needs with other parents/families for support/resources?

Nancy Wiseman / PA CADDRE reply: *Following is a list of ways families can connect with other families:*

Local support groups

Local, state, and national autism organizations

Parent-to-parent networks

Listservs

Conferences

Waiting rooms (during the child's therapies)

Check out the Resource section at www.firstsigns.org.

Linda Tuchman-Ginsberg/Waisman Center, NMHAI reply: *Following are other resources for your consideration.*

Parent to Parent of Wisconsin provides "one-to-one connection for parents new to having a child with special needs, experiencing a time of stress or simply seeking support, resources and information with another parent who has been there." For more information about the strategies and materials utilized by the program, visit: website listed below links to that site and would be a good contact for <http://www.familyresourceconnection.org/ptpow.htm>

The Family Village is also an excellent resource that integrates information, resources, and communication opportunities on the Internet for persons with cognitive and other disabilities, for their families, and for those that provide them services and support. There are many opportunities and resources for parents to connect to other parents built into this site. Visit: <http://www.familyvillage.wisc.edu/>

Family Voices is a national grassroots network of families and friends which advocates for health care services and provides information for families with children and youth with special health care needs. Visit this site to learn more about the resources of Family Voices <http://www.familyvoices.org>

Paul Fujita Asked: How are you proposing to inform parents about the screening tools being used and prepare them for the outcome of the screening?

Nancy Wiseman / PA CADDRE reply: *First Signs has created a [parent brochure](#) for healthcare providers, clinicians, and other professionals who work with young children to share with any parent of a young child from birth through 36 months. The First Signs parent brochure focuses on the importance of monitoring milestones (tucked inside the brochure is a pullout, wallet-size version of the First Signs hallmark developmental milestones), communicating with the PCP about a child's development even when there are no concerns, screening every child on a routine basis, and the importance of taking action when concerns are raised. These brochures can be ordered at www.firstsigns.org. First Signs has also produced a television public service announcement (PSA) that promotes developmental screening. You can view this PSA at http://www.firstsigns.org/press/PSA_Video.htm. It is available to any organization to use and, if interested, you may have your organization's name or logo included at the end. For suggestions on what to say (or not say) in your conversation with the child's parents, please see [Sharing Concern at http://www.firstsigns.org/concerns/sharing.htm](http://www.firstsigns.org/concerns/sharing.htm)*

Linda Tuchman-Ginsberg/ Waisman Center, NMHAI reply: *In addition to the excellent resources Nancy has mentioned above, I found this article on the web about giving "bad news" to families. It is another source of information that addresses key talking points on sharing difficult information.*

New course for doctors who have to break bad news

<http://society.guardian.co.uk/glossary/story/0,,671484,00.html>

Carol Lilly Asked: Can this information be used in other lectures or for training purposes for our residents. We have a web based training system. Thanks:)

NMHAH reply: *yes Carol – please feel free to use the materials. The NMHAH is looking to do some web based training as well. We would love to talk to you about this. Please let us know if we can be of further assistance to you.*

Cynthia Hockman Asked: Will we be able to access printable copy of today's presentation to have websites that were discussed?

NMHAH reply: *the power points are posted on our National Medical Home Autism Initiative website in an html format at <http://www.waisman.wisc.edu/nmhai/WHATSNEW.HTML> If you need the actual power point format please let me know and I can send those by email.*

Deena Margolis Asked: Several of the presentations refer to coordination of services and referrals among various organizations. One of the issues that is often raised is that of sharing confidential medical information. How have these types of confidentiality issues been addressed by other initiatives. For example, are there sample MOUs or agreements in place that can be adapted for use by other initiatives?

Linda Tuchman-Ginsberg/Waisman Center, NMHAH reply: *Parents can sign a release of information for exchange of information among various organizations (initiated by any of the organizations). The approach addresses both the educational (FERPA) and health care (HIPAA) confidentiality requirements. Furthermore, IDEA allows for release of information with prior parental consent.*

It is an excellent idea to address these matters in interagency agreements. You may want to include language about sharing information related to screening practices in general as well as specific practices related to release of information. If anyone has such a sample, it would be great to learn about that.

Some communities have created passbooks that belong to the family. The family carries this card/passbook like an immunization card so that they have the information to share with physicians and other providers. We have had inconclusive discussions about what would be included. Would you want to include screening results or only the dates, locations and ages screening was conducted along with contact information for the person who did the screening.

Given that many states now have immunization records on file, there may be some possibilities of building a system for reporting screening results online so that a family could access this information as they do their child's immunization records.

This is another excellent source of information regarding the coordination of early identification efforts:

TRACE: Tracking, Referral and Assessment Center for Excellence Web site. *The major goal of TRACE is to identify and promote the use of evidence-based practices and models for improving child find, referral, early identification, and eligibility determination for infants, toddlers, and young children with developmental delays or disabilities who are eligible for early intervention or preschool special education. <http://www.tracecenter.info/early.php>*

Maria Bravo asked: Strategies/suggestions for outreach to Native American reservations/tribes

Linda Tuchman-Ginsberg/Waisman Center, NMHAH reply: *One of the strategies we routinely talk about in Wisconsin is having contact with the Health Clinics, Early Childhood and other Maternal and Child Health Programs on the reservations. It is also helpful to develop and nurture a relationship with a professional or family member of the tribe who can serve as a liaison to the members of the tribe or be hired as a service coordinator with a program such as Birth to 3 early intervention. You might learn that there are already screening initiatives in place on that reservation or in an Indian community that you would want to learn more about.*

We have also heard that it is essential to maintain ongoing communication regarding any shared activity. For example, if a referral is made for screening or early intervention, it is important to communicate that information to the tribal contact person(s). It is helpful to identify what occurred and to propose or discuss strategies for coordinated follow up. Perhaps there is ongoing activity being conducted by the tribe or reservation that would enhance the service your practice/program/agency has provided. Perhaps there is follow up that could be provided by the tribal/reservation contact person(s) on behalf of a child and family.

Tribes with Bureau of Indian Affairs (BIA) schools have early intervention, Part C funds have a responsibility for child find and coordinating with early intervention, Part C programs and other resources to assist families in finding their way to services. It could be helpful to learn if there are BIA schools with Part C funds on the reservations in your community.

I would suggest exploring the resources within your state or geographic area.

Peggy Stemmler asked by email: Do other states easily share results of early intervention screening and interventions? We have difficult getting information back to the PCP, with the rationale that FIRPA prevents information sharing.

Linda Tuchman-Ginsberg/Waisman Center, NMHAI and Evelyn Shaw /NECTA reply: Parents can sign a release of information to a primary care physician (either initiated by the early intervention program or initiated by the physician). IDEA allows for release of information with prior parental consent. To develop positive partnerships and ongoing communication with physicians, we encourage early intervention programs to build this practice into their routine activities. It can be helpful to develop a template for a reply letter to a referring physician and to include this practice in a check list of activities for service coordinators to complete throughout the early intervention process.

Peggy Stemmler asked by email:

When a child does not qualify for early intervention, but developmental concerns exist, what resources are available when the specialty referral network (therapies, etc) is spotty?

Linda Tuchman-Ginsberg/Waisman Center, NMHAI reply: If a child is not found eligible for early intervention, one of the responsibilities of the eligibility team is to offer to re-screen. This is one option for monitoring a child's development to make sure that concerns don't increase with time. The other role of the eligibility team is to help a family better understand their child's development and suggest other community resources that may more appropriately support a child's needs. Consider what resources or programs are available in the community to support all children and families. Consider how the child's development might be advanced within those settings. What preschool or child care centers are available in your community? How could a list of suggestions from early intervention assist that child and family to benefit from community programs? What about Early Head Start or Head Start. Not all children in Head Start are required to meet the income guidelines. What about family resource centers or drop in programs? The answer may not have to lie with therapy resources if they are not readily available, although, this is often an alternative for children who are not eligible.

Peggy Stemmler asked by email: I have had feedback from pediatricians asking what proof there is that they are not doing a good job. I know of Judy Palfrey's study from the late 90s. Any newer resources?

Nancy Wiseman reply: Sand N, Silverstein M, Glascoe FP, Gupta VB, Tonniges TP, O'Connor KG. "Pediatricians' reported practices regarding developmental screening: do guidelines work? Do they help?" Pediatrics. 2005;116 :174 –179

Peggy Stemmler asked by email: Also, what evidence is there that early intervention in children at risk for delays or with mild delays makes a difference? I know of the EI evidence for more significant interventions.

Nancy Wiseman reply:

1. Bailey, D. B. Jr, Hebbeler, K., et al. Thirty-Six-Month Outcomes for Families of Children Who Have Disabilities and Participated in Early Intervention. *Pediatrics* 2005 116: p. 1346-1352
2. Reynolds AJ, Temple JA, Robertson DL, et al. Long term effects of an early childhood intervention on educational achievement and juvenile arrest: a 15 year follow up of low income children in public schools. *JAMA*. 2001; 2335-2346.
3. Gombi DS, Lamer MB, Stevenson CS, et al. Long term outcomes of early childhood programs: analysis and recommendations. *Futures of Children*. 1995; 5: 6-24.

Linda Tuchman-Ginsberg and Evelyn Shaw reply: Additional resources-

1. What Is Early Intervention? U.S. Department of Education
<http://www.kidsource.com/kidsource/content/early.intervention.html#contents>

2. Effectiveness of Early Intervention
Resources from NECTAC website
<http://www.nectac.org/chouse/digests.asp#effec>

Carol Lilly asked: Do you have specifics regarding your negotiation with Medicaid that can be used by other areas as talking points? – *no reply given at this time*

Questions for Dr. Duby / AAP: (in process)

Lucy Gibson Asked: Please give us more information about using a Wood's lamp for screening purposes.

Helen Keith Asked: In Dr. Duby's presentation and others, what are the best practices that health care providers have for working with families in the coordination of further evaluation and early intervention services?

Helen Keith Asked: What are the characteristics of coordination among medical homes, families and early intervention/community resources?

COMMENTS

Helen Keith commented: Nice job everyone as it impacts all children through a focus on autism and related issues.