Putting Neuromotor Screening Into Practice: Webinar 3

June 27, 2013
11:00 am Central
<table>
<thead>
<tr>
<th>Agenda Item</th>
<th>Speaker</th>
<th>Time</th>
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<tbody>
<tr>
<td>Welcome and Project Introduction</td>
<td>Pat Heinrich, RN, MSN, QI Advisor</td>
<td>5 min</td>
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<tr>
<td>Discuss Action Plans and Feedback</td>
<td>Pat Heinrich facilitate</td>
<td>20 min</td>
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<tr>
<td>Educational Content – Patient Care if Motor Delay is Identified</td>
<td>Dipesh Navsaria, MPH, MSLIS, MD</td>
<td>25 min</td>
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<tr>
<td>Next Steps Introduce Next Action Plan - <em>Develop a System for Referral and Monitoring in the Medical Home</em></td>
<td>Pat Heinrich</td>
<td>10 min</td>
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Action Period 2: Feedback

• Reflections:

“It was hard to complete all positions especially horizontal suspension and protective extension in older ones “6mo a/o especially heavy babies. Prone and Side lying exam are time consuming.”

• On the tools, labs and the MRI:

“ASQ would be a lot better than PEDS( we are using currently) for NMS screening but ASQ is more time consuming. I would be still hesitant to do MRI as a screening tool for poss upper motor neuron problems before referral to pediatric neuro’

“We still remain skeptical about the need for hypertonic children to undergo an MRI and would like further discussion on this topic. The article indicates that the American Academy of Neurology recommends it for children suspected of having cerebral palsy. Does it need to be done for children with known asphyxia at birth or born extremely low birth weight or premature? Is the MRI to look for specific findings that will alter their treatment or to rule out other possible conditions such as schizocephaly? Would it eliminate a lot of normal (and possibly unnecessary) MRIs if it is done on children with hyper tonicity and another physical exam finding such as hemiplegia?”

“we prob will not do mri, when musc dystrophy is added to newborn screen not sure we will get labs”

“I think it's relatively straightforward and will be relatively easy to incorporate into our practice. Most surprising is the recommendation for MRI on all children that have increased tone.”

“Surprising is the recommendation to test for low thyroid in otherwise normal low tone children who had a normal newborn screen”
Action Period 2: More.....

• A Question
  “what is purpose of our feedback when algorithm already came out. we always do neuro exam for well checks- do some places not do this?”

• What do you need from others?
• What do you want to share with others?
• What did you learn?
  – How has your care impacted patients?
  – Suggestions for changes to the algorithm?
• Are you able to implement the steps in the algorithm?
Objectives

At the end of this presentation, the participants will be able to

• Develop a database of referral contacts
• Connect with and develop a partnership with at least one referral agency
• Plan system for planned follow up care visits
Patient Care if Motor Delay is Identified

Dipesh Navsaria, MPH, MSLIS, MD
University of Wisconsin
School of Medicine & Public Health
Madison, Wisconsin

Neuromotor Screening Expert Panel
American Academy of Pediatrics
• In the past 12 months, I have not had a significant financial interest or other relationship the manufacturers of products or providers of the services that will discussed in my presentation.

• This presentation will not include discussion of pharmaceuticals or devices that have not been approved by the FDA or of unapproved or “off-label” uses of pharmaceuticals or devices.

— Dipesh Navsaria, MPH, MSLIS, MD
AAP Neuromotor Screening Expert Panel

- Nancy A. Murphy, MD (Chairperson, Council on Children with Disabilities)
- Paul H. Lipkin, MD (Council on Children with Disabilities)
- Garey H. Noritz, MD (Council on Children with Disabilities)
- Howard M. Saal, MD (Committee on Genetics)
- Michelle Macias, MD (Section on Developmental and Behavioral Pediatrics)
- Max Wiznitzer, MD (Section on Neurology)
- John F Sarwark, MD (Section on Orthopedics)
- Joseph F Hagan, Jr., MD (Bright Futures Initiatives)
- Dipesh Navsaria, MD, MPH (Primary Care)
- Peter Leon Rosenbaum, MD, (AACPDM)
- Georgina Peacock, MD, MPH, (CDC/NCBD)
- Mark Swanson, MD, MPH, (CDC/NCBD)
- Marshalyn Yeargin-Allsopp, MD, (CDC/NCBD)

Funded by the Centers for Disease Control and Prevention/National Center on Birth Defects
Identifying Children With Motor Delays: An Algorithm for Surveillance and Screening
Referral: Early intervention, subspecialist consultation, CSHCN identification
<table>
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<tr>
<th>Indications for prompt referral</th>
<th>Implications</th>
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<tbody>
<tr>
<td>Elevated CK to greater than 3X normal values (males and females)</td>
<td>Muscle destruction such as in Duchenne Muscular Dystrophy, Becker Muscular Dystrophy, other disorders of muscles</td>
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<td>Fasciculations (most often but not exclusively seen in the tongue)</td>
<td>Lower motor neuron disorders (Spinal Muscular Atrophy); risk of rapid deterioration in acute illness</td>
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<tr>
<td>Facial dysmorphism, organomegaly, signs of heart failure, and early joint contractures</td>
<td>Glycogen storage diseases (mucopolysaccharidosis, Pompe Disease may improve with early enzyme therapy)</td>
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<td>Abnormalities on brain MRI</td>
<td>Neurosurgical consultation if hydrocephalus or another surgical condition is suspected.</td>
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<td>Respiratory insufficiency with generalized weakness</td>
<td>Neuromuscular disorders with high risk of respiratory failure during acute illness (consider inpatient evaluation)</td>
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<td>Loss of motor milestones</td>
<td>Suggestive of neurodegenerative process</td>
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<tr>
<td>Motor delays present during minor acute illness</td>
<td>Mitochondrial myopathies often present during metabolic stress</td>
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Diagnosis and Treatment

- Children with motor delays should be simultaneously referred to:
  - Medical Specialists (Neurology, DBP, NDD, PM&R) for Diagnostic testing and medical treatment
  - Therapy and Early Identification Services for motor treatment

Pletcher, 2010
Children’s Hospitals’ Pediatric Specialist Shortages

*"All Other" includes 33 different pediatric specialties.*
Specialties with most frequently reported vacancies ≥ 12 months

<table>
<thead>
<tr>
<th>Specialty</th>
<th>Vacancy Rate</th>
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<tbody>
<tr>
<td>Pediatric Neurology</td>
<td>38.8%</td>
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<tr>
<td>Pediatric General Surgery</td>
<td>29.9%</td>
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<tr>
<td>Developmental Pediatrics</td>
<td>28.4%</td>
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<tr>
<td>Pediatric Gastroenterology</td>
<td>25.4%</td>
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<tr>
<td>Pediatric Pulmonology</td>
<td>25.4%</td>
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<tr>
<td>Pediatric Rheumatology</td>
<td>25.4%</td>
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Pediatric Specialty Shortages Burden Children and Families

• Average Wait Time
  – Developmental Pediatrics  14.5 weeks
  – Genetics 10.8 weeks
  – Pediatric Neurology 8.9 weeks

Children's Hospital Association 2012
Primary care considerations
Referral: Early intervention, subspecialist consultation, CSHCN identification
Observation

• Mild abnormalities without red flags may be closely followed through observation.
  – A plan for immediate follow-up in the event of new or worsening sx is important.
    • Regression of motor skills
    • Loss of strength
    • Concerns with respiration or swallowing

• A planned, scheduled return visit earlier than the next Bright Futures visit may be appropriate, including surveillance or additional screening.
Education & Other Referrals

• Education of family regarding concerns is key
  – May not be as in-depth as when a definitive dx is made, but should not be omitted or glossed-over.
  – Address anxiety and uncertainty.

• Refer to early intervention or special education in even suspected neuromotor delay.

• Likewise for PT/OT
Medical Referrals

• Each medical home should develop their own local resources and network of subspecialists as these will vary greatly.

• Direct provider-to-provider communication is recommended when red flags are identified.

• Consider photographs or video to expedite evaluation if secure transmission is available.
Chronic Condition Management

- Identify child has having special health care needs, even prior to definitive diagnosis.
- Registry
- Written care plans, explicit comanagement with specialists, patient education, sharing of information.
- Comprehensive needs assessment and outcomes.
- Community-based support, including respite care, parent/advocacy organizations.
- Additional benefits (SSI, MA, waivers, etc.)
Conclusions

• The Primary Care Physician should implement screening for all developmental delays, including motor delays.

• This screening process should include use of a validated screening instrument and a careful assessment of the child’s tone.

• Initial workup for neuromotor delays should occur in the medical home:
  • CK and TSH when the child has low or normal tone
  • MRI of the brain when the child has increased tone
  • Children with neuromotor delay should be referred simultaneously for diagnosis and treatment
  •Pediatricians should look for “red flags” to determine which children with neuromotor delay need expedited referral to specialists
Questions?
<table>
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<tr>
<th>Hold a team meeting to:</th>
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<tbody>
<tr>
<td>1. Review criteria for referral and plan how to implement changes if needed to identify criteria for referral in your office flow</td>
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<tr>
<td>- Plan a process to identify high risk patients and those with abnormal lab or imaging results</td>
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<td>- Plan how to “flag” charts of patients who are identified in a. above</td>
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<td>- Review process flow from AP 1 to determine scheduling additional time for f/u visits is needed</td>
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<tr>
<td>- History or exam concerning</td>
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<tr>
<td>- Abnormal neuroimaging</td>
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<td>- Abnormal labs</td>
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<tr>
<td>2. Plan changes needed to identify referral sites</td>
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<tr>
<td>- Does your team have an up to date database of local resources?</td>
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<td>- Do you have a good process for communication to and from referral sites?</td>
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<td>- Do you get feedback from patients who visit referral sites?</td>
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# Action Plan 3

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<tr>
<th>3. Develop referral database</th>
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<tr>
<td>4. Consider local resources</td>
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<tr>
<td>- Seek help from Parent partners to develop data base of referral agencies</td>
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<tr>
<td>- Plan staff role in development of referral database (consider use of care coordinator)</td>
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<tr>
<td>- Identify or develop referral documentation tool(s)</td>
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<pre><code>|  - Referral note or letter |
|  - Fax back form |
|  - Other |
</code></pre>
<p>| 5. Plan implementation of a fax back form for immediate feedback from referral site |</p>
  - See Sample Fax Back Form at [http://internet.dssc.uic.edu/forms/medicalhome/FaxBackForm2.pdf](http://internet.dssc.uic.edu/forms/medicalhome/FaxBackForm2.pdf) |
| 6. Plan how to obtain feedback from Patient/Family after referral contact to evaluate referral base (time to appointment and satisfaction with care provided, communication skills etc.) |
  |  - Consider and plan how to obtain text, post card, or phone follow up to assure contact made and care satisfactory to patient |
  |  - Include expected time for feedback and prompts/reminders in EHR |
  |  - Alternately consider and plan how to query patient at next visit to your office |
# Action Plan 3

<table>
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<tr>
<th>Date</th>
<th>Task</th>
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| July 17, 2013      | 7. Reach out to one referral site to develop partnership with one key referral agency  
                    |   - Initiating a connection with one local agency will help you work as partners to plan interventions and processes for referrals/feedback etc. for patients in your practice |
| August 9, 2013     | 8. Complete AP 3 Brief Survey at: [INSERT LINK]                      |
| August 10, 2013    | 9. Collect feedback from parents about referrals they visited  
                    |   - Do a PDSA on #6 above                                          |
| August 15, 2013    | 10. Plan feedback to AAP on Follow-up Conference Call  
                    |   - Prepare to share on the next webinar  
                    |   - Questions:  
                    |   |   • What do you need from others?  
                    |   |   • What do you want to share with others?  
                    |   - What you learned  
                    |   |   • How your care impacted your patients  
                    |   |   • Suggestions for changes to the algorithm  
                    |   |   • Other  
                    |   - What you thought about the Web&Action model of learning/improving  
                    |   |   • What did you like? What can be improved? |
Next Steps

• Complete Action Plan 3 Brief Survey
  — August 9th

• Follow-up Conference Call
  — August 15, 2013 (5:00 pm Central Time)

• Complete post-survey and project evaluation
  — August 30, 2013
Project Resources

• Project Listserv
  NMS@listserv.aap.org
  – Communicate with other teams and project leaders

• Project Web page
  http://aap.org/quiiNMS
  – Find project materials, tools, Webinar recordings
Contact Us!

- Jill Healy, MS, QuIIN Program Manager  
  jhealy@aap.org | 800/433-9016, ext. 7122
- Rachel Daskalov, PEHDIC Program Manager  
  rdaskalov@aap.org | 800/433-9016, ext. 7863
- Pat Heinrich, RN, MSN, Quality Improvement Advisor  
  pat@heinrichllc.com | 617/686-6161

- Acknowledgement
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Questions