



# Washington State Medical Home E-Update

News from the Washington State Medical Home Partnerships Project

Spring 2013

## New Clinical Resources to Help Serve Children and Youth with Special Needs

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*This issue contains several new clinical resources for Autism, Down syndrome, motor delays and oral health care that we thought members of Medical Home Leadership Network (MHLN) teams and other partners would find helpful.*

*We review a lot of journals and e-newsletters in our work, but don't see everything. We appreciate recommendations from the Network for news and resources to share with the MHLN. Thank you Susan Atkins and Lawrie Williams from Parent to Parent for letting us know about the well made Portland, Oregon video with tips for health care providers about how to best share a new diagnosis of Down syndrome with families.*

*Keep the suggestions coming!*

*--Katherine TeKolste, MD, Kate Orville, MPH and Amy Carlsen, RN, MHPP staff*

## The New DSM-5 – Overview of Changes in Autism Diagnosis

On May 18th, the American Psychiatric Association (APA) released a new version of the Diagnostic and Statistical Manual of Mental Disorders, or DSM. The DSM is the standard reference that healthcare providers use to diagnose mental and behavioral conditions. The new version is referred to as the “DSM-5.”

There has been a lot of confusion about what the changes will mean for children and adults on the Autism Spectrum. Autism Speaks has a list of Answers to Frequently Asked Questions about the DSM-5:

<http://www.autismspeaks.org/dsm-5/faq>

The Autism Blog at Seattle Children's sat down recently with Dr. Bryan King, Director of Seattle Children's Psychiatry and Behavioral Medicine and Autism Center, and filmed a brief (3'55") user friendly [video](#) explaining some of the main changes of interest to families to clinicians.

Highlights from Dr. King's discussion include:

- There is now **one diagnosis of Autism Spectrum Disorder**- The new classification system eliminates the previously separate subcategories on the autism spectrum, including Asperger syndrome, Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS), childhood disintegrative disorder and autistic disorder. These subcategories will be folded into the broad term autism spectrum disorder (ASD). The DSM-5 text includes directions for clinicians about how to transition from using established

diagnoses. **Individuals with well established diagnoses should be given the diagnosis of ASD but should not need to go be rescreened or assessed.**

- The transition to a single diagnosis of ASD is now supported by the use of **specifiers**. Clinicians should indicate whether there are impairments in language, impairments in intellectual ability, or medical conditions such as Fragile X or seizure disorder.
- The new DSM-5 now includes **sensory issues** (hypo- or hyper-sensitivity) or **unusual interests** that may indicate autism.
- It is a given that everyone with the diagnosis will need some services or support, but the new **severity criterion** meant to give indication of the level of services and supports required.

The Autism Blog features regular posts from physicians, nurses, psychologists, speech therapists and family resource staff who are knowledgeable about the diagnosis and the latest in treatments and therapies and engaging writers. The blog also posts notices of upcoming Seattle and telehealth classes for families on caring for children and youth with ASD. <http://theautismblog.seattlechildrens.org/>

## Down Syndrome - New Video and Other Resources on Sharing Sensitive News

Down syndrome occurs in 1 of every 733 births. The majority of children are still diagnosed post-natally. Many parents of children with Down syndrome have expressed dissatisfaction with how they learned about their child's diagnosis.

The following resources can improve how you share difficult or sensitive news and will help guide you in determining:

- Who is the best person to communicate the diagnosis?
- When is the best time to share this information?
- Where is the best setting in which to deliver the news?
- What information should be given?
- How should this information be communicated?

### Resources:

- **Video for health care providers created by the Down Syndrome Network Oregon.** The brief (3'44") video has two parts- first part is hosted by a Portland, OR physician who is also the father of a child with Down syndrome and who shares tips for physicians and other primary care providers about how to best talk with and support families receiving a new diagnosis of Down syndrome. The second part of the video shows children and youth with Down syndrome participating in full lives. This video was brought to our attention and recommended to us by several Washington State Parent to Parent Coordinators, including one who is a mother of young adult with Down syndrome (thank you!).  
<http://vimeo.com/66687709/>
- From the Down Syndrome Diagnosis Study Group: '**Postnatal Diagnosis of Down Syndrome: Synthesis of the evidence on how to best deliver the news**' by Skotko BG et al – as mentioned in 'Caring for the Child with Down Syndrome'. *Developmental and Behavioral News, Spring 2013* (published by the AAP Section on Developmental and Behavioral Pediatrics)  
[www.pediatrics.org/cgi/content/full/124/4/e751](http://www.pediatrics.org/cgi/content/full/124/4/e751)
- **Sharing Sensitive News Information** from the WA State Medical Home Partnerships Project Website: [www.medicalhome.org/physicians/share\\_badnews.cfm](http://www.medicalhome.org/physicians/share_badnews.cfm)

## **‘Motor Delays: Early Identification and Evaluation’ New AAP Clinical Report**

With support from the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention, the American Academy of Pediatrics (AAP) convened a Neuromotor Screening Expert Panel with physicians from a wide range of specialties. The panel’s Clinical Report on *Motor Delays: Early Identification and Evaluation* was published the June, 2013, issue of *Pediatrics*. The report provides guidance for screening and workup of a child with a suspected motor delay, with an accompanying algorithm for systematically screening for motor delays.

The first step is not specific to motor delays, but involves generalized developmental screening using standardized screening tools at the 9-, 18-, 30- and 48-month well-child visits, as well as any time families or clinicians raise concerns. If any concerns related to motor development are identified, the clinical report advises practitioners on elements of a thorough neurologic history and examination, as well as laboratory and imaging study recommendations. The clinical algorithm outlines a number of red flags that should prompt timely referral to specialists – neurologist, developmental pediatrician, geneticist and/or physiatrist. Children with suspected motor delays should also be referred for treatment by early intervention programs and therapists.

Link: <http://pediatrics.aappublications.org/content/131/6/e2016.abstract?rss=1>

## **‘Oral Health Care for Children with Disabilities’ New AAP Clinical Report**

Children with special health care needs are at greater risk than ‘typically-developing’ children for developing oral health problems and dental disease. And they are more likely to have unmet dental needs and poor access to dental care. Children with developmental disabilities may have difficulty performing self-care skills and regular, routine dental hygiene, e.g. as a result of motor or intellectual limitations. They may have oral aversions, have difficulty with oromotor coordination which require dietary alterations such as a liquid or pureed diet, or have impaired salivary function. Poor oral health may have secondary effects which impact a child’s eating, sleep patterns and ability to focus due to discomfort or more serious medical issues such as aspiration pneumonia or systemic infection. In addition, medications may have side effects that adversely impact oral health –e.g. gingival hypertrophy or decrease saliva production.

In *Pediatrics* (March 2013), the American Academy of Pediatrics (AAP) published a new clinical report on [‘Oral Health Care for Children with Disabilities’](#). It includes information on how to incorporate oral health assessment and education into well-child visits. You can access the [Oral Health Risk Assessment Tool](#) online. The authors recommend children with developmental disabilities establish a dental home by 1 year of age. The report outlines oral health risk factors affecting children with developmental disabilities.

Pediatricians can meet Maintenance of Certification (MOC) Part 4 requirements while improving oral health care for children with the newly released EQIPP online course "[EQIPP Oral Health in Primary Care](#)". (Registration fee required)

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MHLN Community Teams: [www.medicalhome.org/leadership/teams.cfm](http://www.medicalhome.org/leadership/teams.cfm)

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- ✦ The Washington State Department of Health
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