Many primary care providers fail to regularly screen the development of children in their practice. In addition, although families of children with autism spectrum disorder (ASD) report having a personal doctor or nurse and a usual source of care, they also report their children have unmet health care needs, have difficulty receiving referrals, and receive care that is not family-centered nor coordinated.

Objective:
Our objective is to improve the screening, referral and management of children with ASD and other developmental disabilities (DDs) in the medical home.

Description:
This project is one activity of our state autism implementation grant funded by the US Maternal and Child Health Bureau and administered by the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN), OHSU. Project staff have worked with pediatric practices in 6 sites to implement a 6 month quality improvement (QI) program focused on children with ASD and other developmental disabilities (DD). 2 sites have completed the 6 month QI project, 3 sites are on-going and a 6th practice stopped participation prior to completion due to the pediatrician’s move from the area. The Oregon Pediatric Improvement Project (OPIP) and the Oregon Rural Practice Research Network (ORPRN) at OHSU provide support and facilitation of practice change. 4 of the 6 practices who have participated are the practices of pediatricians on our local Autism Specialists and Developmental Disability staff are introduced. The Center for Disease Control’s Learn the Signs Act Early materials are distributed to the health care providers who attend. Then each practice receives 3 site visits and monthly phone conference calls over the next 6 months. The office team is provided introductory information including the Medical Home Index-Revised Short Form (MHI:RSF, Center for Medical Home Improvement, 2012) and the document, A Medical Home for Children with Developmental Disabilities including Autism Spectrum Disorder (ASD, Nickel, 2014). This document lists a number of issues which might be addressed by the office’s QI team. Examples include:
- Pre-visit planning
- Use of a Shared Care Plan and Next Steps Plan
- Resources and Materials for families

Methods:

Who is on the QI team?  a pediatric champion, office care coordinator, nurse manager and/or the clinic manager and a parent of a child with ASD.

The steps in practice facilitation:
Initially the Oregon Pediatric Society’s Autism 101 for PCPs module is presented to the practice and others in the local community. It covers autism screening with the M-CHAT-R/F, referral to services, and management of common co-occurring medical and mental health problems. A parent reviews their child’s story and local Autism Specialists and Developmental Disability staff are introduced. The Center for Disease Control’s Learn the Signs Act Early materials are distributed to the health care providers who attend.

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- Pre-visit planning
- Care Coordination (includes identification of office Care Coordinator)
- Annual chronic condition management visits
- Use of a Shared Care Plan and Next Steps Plan
- Resources and Materials for families

Project staff conduct the Initial Site visit with the practice team.
- Project staff review goals and objectives for the grant’s enhancing the medical home activity
- The office team completes the MHI:RSF and reviews the Medical Home document to assist with identifying QI objectives and activities
- Project staff review QI issues other practices have addressed
- Office team begins to identify their initial QI objectives and activities
- Office team discusses possible parent partners who would join the office QI team. Support and training is provided to the Parent Partner by the OCCYSHN staff.
- Date and time of follow-up phone conference is established to clarify QI objectives and activities.

Technical Assistance and Support from OCCYSHN:
- Online discussion group/forum, https://sakai.ohsu.edu

Progress to date:
- 5 practices now actively participating
- Quality Improvement (QI) Issues addressed and practice changes
  - All practices save 1 doing regular developmental screening as per AAP guidelines (screening will be addressed by the 5th practice’s QI activities)
  - Social stories/picture schedules of office visit on practice web sites
  - QI activity to increase yearly well child/chronic condition management visits
  - Pre-visit planning using “Tips for a successful visit” for both admin staff and parents, use of AAP’s “Family –Centered Care Coordination Tool”
  - Initiation of buzzer system for parents/children waiting in/outside office when MD ready to see child
  - Identification of office care coordinator (2 practices already had Care Coordinators)

Lessons Learned:
- Parent Partners are important participants and champions of the process
- Do not schedule QI project to start in the Winter (respiratory disease season), or start in the Summer (vacations), or when practice is implementing a new electronic medical record (EMR)
- Life happens (one pediatrician moved out of state, another left on a 4 month locum tenens, serious illness in family of another pediatrician)

Project Evaluation:
The project’s Evaluation Plan includes pre and post-MDI and Parent Partner surveys, pre and post- MHI:RSF, pre and post-START Autism 101 module surveys, and # of issues addressed by the QI team and # and type of changes in office procedures. Results are pending completion of the project in the remaining 3 practices.

For further information:
Contact Dr. Robert Nickel, nickelr@ohsu.edu and review the project’s web page at OCCYSHN.org and select “Community-based ASD Identification”